PERCEPTIONS OF PSYCHOSOCIAL DEFICITS POST TWO YEARS AS EXPERIENCED BY CLOSED HEAD INJURED ADULTS AND THEIR FAMILIES: AN EXPLORATORY STUDY

A thesis submitted in partial fulfilment of the requirements
for the
Degree of

MASTER OF ARTS
in Psychology
UNIVERSITY OF CANTERBURY

by

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University of Canterbury
1995.

THIS THESIS IS DEDICATED TO

PROFESSOR DAVID LLOYD.

ACKNOWLEDGMENTS

There are a number of people I would like to acknowledge who have in some way contributed to this research. However most importantly, I would like to express my warmest thanks to all the CHI participants and their families for allowing me to share their experiences. Most participants in this study volunteered to take part in this research in the hope that it may assist other CHI individuals and their families in some way. Without their help this thesis would not have been possible.

I would like to acknowledge my supervisor, Dr. Steve Hudson for his advice and guidance throughout the production of this thesis.

My sincere thanks to Professor Alan Clarke, Dr. Linda Newstrom and Elizabeth Waugh for encouraging me to take an interest in this very important area. I would also like to thank Louie Loopecker, Field Officer, Head Injury Society, Christchurch, for all his practical help in assisting me to make connections with CHI individuals and their families. In addition, I would like to acknowledge the Special Interest Group, Head Injury Society, from whom I gained some understanding of the services (and the lack of the same) that were currently available to head-injured individuals and their families.

Special thanks goes to my family, Wayne and Petrea, who have not only supported and encouraged me throughout this project, but have also provided practical assistance and humourous relief.

TABLE OF CONTENTS

	Page
Acknowledgments	**ii**
Table of Contents	**iii**
List of Tables and Figures	**vii**
Abstract	**ix**
CHAPTER ONE: INTRODUCTION	
PART 1: GENERAL INTRODUCTION	1
1.1. Definition of closed head injury	3
PART 2: LITERATURE REVIEW ON DEFICITS OF CLOSED HEAD INJURY	5
2.1. Cognitive impairment following closed head injury	7
2.1.1. Attention and Concentration	9
2.1.2. Learning and memory problems	10
2.1.3. Higher cognitive/executive functioning	11
2.1.4. Information processing	12
2.1.5. Language difficulties	13
2.2. Emotional and behavioural impairment following closed head injury	14
2.3. Physical impairment following closed head injury	21
2.4. Vocational adjustment	24
2.5. Family issues	27
2.6. Methodological limitations	34

2.7. Conclusions 35

PART 3: RATIONALE AND AIMS OF PRESENT STUDY 36

3.1. Hypotheses 37

CHAPTER TWO: METHOD

PART 1: TREATMENT OF DATA 50

PART 2: PARTICIPANT CHARACTERISTICS 50

PART 3: EDUCATION 53

PART 4: TIME OF ACCIDENT AND SEVERITY OF INJURY 53

PART 5: RELATIONSHIP STATUS 53

PART 6: EMPLOYMENT 55

PART 7: DETAILS OF HEAD INJURY 57

PART 8: THE CLOSED HEAD INJURY PHYSICAL SCALE 59

PART 9: THE CLOSED HEAD INJURY COGNITIVE SCALE 63

PART 10: THE STANDARDISED SCALES 69

10.1. The Beck Depression Inventory 69

10.2. State-Trait Anxiety Inventory 69

10.3. The State-Trait Anger Expression Inventory 71

PART 11: THE HEAD INJURY BEHAVIOURAL SCALE 75

CHAPTER FOUR: DISCUSSION

PART 1: GENERAL DISCUSSION 84

1.1. Physical Outcome 86

1.2. Cognitive Outcome 88

1.3. Emotional Outcome 91

1.4. Behavioural Outcome 96

1.5. Vocational Outcome 98

1.6. Rehabilitation suggestions 100

PART 2: LIMITATIONS OF THE PRESENT STUDY 102

PART 3: DIRECTIONS FOR FUTURE RESEARCH 105

PART 4: SUMMARY AND CONCLUSIONS 106

REFERENCES **109**

APPENDICES

One:	Consent Forms	121
Two:	Information sheet	122
Three:	Part A: Closed Head Injury Biographical Details	124
Four:	Part B: Details of the Head Injury	126
Five:	Closed Head Injury physical scale	127
Six:	Closed Head Injury cognitive scale	130
Seven:	Head Injury Behavioural Scale (both versions)	135
Eight:	Beck Depression Inventory (BDI)	141
Nine:	State-Trait Anxiety Inventory (STAI-Y1, STAI-Y2)	144
Ten:	State-Trait Anger Expression Inventory (STAXI)	146
Eleven:	Details/types of head injury suffered by closed head injured individuals	150
Twelve:	Coding Schedule: Physical/Cognitive Scales	152
Thirteen:	Coding Schedule: Head Injury Behavioural Scale	154

Fourteen:	Advertisement for recruitment of participants	156
Fifteen:	Classification: Post Traumatic Amnesia Scale (PTA)	157

LIST OF TABLES AND FIGURES

TABLES

		Page
1.	Demographic Details	51
2.	Highest premorbid educational level (head injury group)	52
3.	Percentage of people grouped according to their date of accident	52
4.	Closed head injury subjects' relationship status pre and post head injury	54
5.	Employment status pre and post head injury for closed head injury subjects	56
6.	Types of head injury	58
7.	Areas of difficulty - participants and family members ratings of deficits in the closed head injury physical scale	60
8.	Areas of difficulty- participants and family members ratings of deficits in the closed head injury cognitive scale	64
9.	Beck Depression Inventory scores as perceived by closed head injured subjects	70
10.	Anxiety scores using the STAI-Y1 and STAI-Y2 scales as perceived by the closed head injured subjects	70
11.	State-Trait Anger Expression Inventory (staxi) scores as perceived by the closed head injured subjects	72

FIGURES

1.	Participants and family members ratings of deficits in the closed head injury physical scale	61
2.	Participants and family members ratings of deficits in the closed head injury cognitive scale	65
3.	Time comatosed by closed head injured subjects	67
4.	Head Injury Behavioural Scale as perceived by closed head injured subjects	77

5.	Head Injury Behavioural Scale as perceived by family members	78
6.	Differential in identification that behavioural problems (moderate to marked) are evident as perceived by family members and closed head injured subjects	79
7.	Differential in identification that physical problems (moderate to marked) are evident as perceived by family members and closed head injured subjects	80
8.	Differential in identification that cognitive problems (moderate to marked) are evident as perceived by family members and closed head injured subjects	81

ABSTRACT

The purpose of this exploratory study was to examine responses of 18 closed-head injured adults with moderate to extremely severe head-injury (according to the Post-Traumatic Amnesia Scale), and 10 family members. The responses of both these groups was directly compared utilising three scales (Closed head-injury Cognitive Scale, Closed head head-injury Physical Scale & the Head Injury Behavioural Scale) and by utilising three standardised clinical instruments (the Beck Depression Inventory, the State-Trait Anxiety Scale, & the State-Trait Anger Expression Inventory). All the participants in this study took part in a semi-structured interview with the researcher to investigate deficits in four areas of functioning, namely, the physical, cognitive, behavioural and emotional areas. Perceptions of preinjury and postinjury employment status was also evaluated.

The results revealed that significant changes in psychosocial functioning were perceived by all the participants. Specifically, more of the family members tended to rate negative changes in the behavioural area, while the same numbers in both groups perceived the magnitude of changes in the cognitive area. Both groups acknowledged physical impairment, however the CHI participants rated more negative changes in the physical area. In the emotional sequelae, CHI participants indicated some depression, anxiety and anger problems at the time of testing. Substantial negative employment changes were perceived by all the participants. Implications of these results are discussed and suggestions for rehabilitation, especially in the Canterbury area, New Zealand, that were reported by the participants are included.

CHAPTER ONE

INTRODUCTION

1. GENERAL INTRODUCTION

Closed head injury (CHI) has been termed the "silent epidemic" of our time (Bullard & Cutshaw, 1991; Carr, 1993). Due to improved emergency services and improvements in acute care, 400,000 people survive closed head injuries with 100,000 people suffering severe neurological impairment (Bullard & Cutshaw, 1991). In New Zealand some 9,000 people are admitted to hospital with head injuries (Carr, 1993), which represents approximately 170 per week, from these New Zealand statistics records show 3359 intracranial injury admissions in a single year (Smith, 1993). Generalisation from overseas studies reported the expected overall head injury incidence in New Zealand to be between 250-370 per 100,000 (Carr, 1993).

It is becoming recognised that head trauma is now the leading cause of death for persons under the age of 45 years and that some three-quaters of accidental deaths are due to closed head injuries. This has led to a growing awareness that over the past decade or so head injuries continue to constitute a major public health problem both in New Zealand and overseas (Carr, 1993; Jennett, 1989).

Volpe and McDowell, (1990) suggested that there can be no disagreement that the loss of intellect and subsequent personality changes in patients with CHI are catastrophic. Unlike other neurological diseases, traumatic brain injury disables people for 30 to 40 more years. It may create a burden for families and in many cases for society. Modern medicine, although it can save

lives of these patients who formerly may have died, cannot in most cases, restore a damaged brain to normal or to premorbid function (Volpe et al., 1990).

Damage experienced from a closed head-injury is seemingly invisible. The skull in closed head-injury is not penetrated, therefore everything appears intact. While gunshot wounds and other open wounds produce confined and large lesions, closed head injury creates far more diffuse damage (Fenelick & Ryan, 1991). Not only are the groups of cells destroyed, but neuronal connections are vastly disrupted. The effects of this type of head injury is both subtle and complex. (Fenelick, & Ryan, 1991; Gloag, 1985). Physical, cognitive, behavioural and emotional handicaps are documented in literature to be the chief cause of long term disability in closed head-injured persons (Gloag, 1985; Smith, 1994).

It has been estimated that head-injured persons in the 15-24 age group are at a higher risk than the general population for head trauma (Rimel & Jane, 1984). According to Rimel and Jane (1984), a male predominance exists and the difference in gender, in their study, was the greatest between the ages of 15 and 24. The major aetiological factors of closed head injury appear to be traffic accidents, falls and assaults. The less frequent causes are sporting injury, especially boxing and horse-riding, industrial injury and perinatal trauma (McClelland, 1988).

There is a vast amount of literature on the sequelae of closed head injury, however, it was beyond the scope of this study to review all of this work. The focus of the present study was limited to the deficits created by closed head injury in four areas of functioning, namely; cognitive, physical, behavioural and

emotional. In addition, the study investigated vocational and family issues. The main focus of this study was to explore differences in perceptions of the closed head injured individuals and their families in the above four areas of functioning, and how these areas may have affected family and vocational functioning. The participants (both CHI adults and the family members) are also asked to make suggestions regarding rehabilitation, for example, what services they felt are lacking at present and what services they believed should be provided and would be useful for future CHI individuals and their families.

1.1 Definition of Closed Head Injury

It is recognised that there are two distinct types of head-injuries, open head-injuries, where there is obvious damage to the skull, and closed head injury where this is not the case (sometimes also referred to as missile injury and nonmissile injury) (Levin, Benton, & Grossman, 1982). Closed head-injury in more contemporary times has also been termed "Traumatic Brain Injury" (TBI). In a closed head-injury, the injury is less obvious (invisible), the effects of it cannot be seen, however, the CHI suffers many deficits in the physical, behavioural, emotional and cognitive areas. Each individual is unique in the amount and type of damage sustained in a closed head injury, in other words, no two people with a closed head injury may have the same symptoms.

The damage that has occurred to the brain depends on the nature and amount of force that the head receives (Jones, & Lorman, 1988). The brain is surrounded by fluid known as *cerebrospinal fluid* which is encased in the bony skull which provides protection. This bony structure is inflexible and limits and specifies the movement of the brain (Jones, & Lorman, 1988). The impact of an

accident, distinguished by a violent and unnatural movement of the brain within the skull, can produce bruising and shearing as the brain mass rotates within the cranium (Lezak, 1983). Blunt trauma to the head (sustained in closed head-injury) can result, either from the impact of a moving object (acceleration), or when the head and body are decelerated by a stationary or slower moving object (Levin et al., 1982). Linear and rotational acceleration typically co-exist. Blunt trauma to the head can injure the scalp, deform the skull by, in some instances, fracturing it and by shifting the intracranial contents. Intracranial pressure can increase briefly on impact. While blunt trauma associated with acceleration/deceleration impact to the head is the primary mechanism of impact in a closed head injury, according to Levin et al (1982) bone fragments can penetrate the brain tissue in cases of heavy skull fracture.

Damage suffered can be focal or *coup* injury, or the damage can occur on the other side of the brain from point of impact or *contrecoup*, where the individual can sustain significant bruising or *contusions* (Lezak, 1983). Widespread damage is common in CHI causing diffuse injuries to all the parts of the brain to a greater or lesser degree, which may be why the symptomatic picture of each closed head-injured individual varies from person to person.

Secondary damage to the brain can also occur and is life threatening, these include bleeding (*haemorrhage or haematomas*), swelling of the brain tissues (*edema*), cerebral oedema, *seizures*, or post traumatic epilepsy, imbalance of the cerebrospinal fluid (hydrocephalus) and infections. With localised brain injury specific disabilities may occur, however with diffuse injuries many other problems may occur, such as, physical problems (vision, auditory, paralysis, hemiparalysis), cognitive problems (memory, distractability,

concentration, executive functions etc.), emotional problems and behavioural problems (aggressiveness, anger, depression etc.) (Kolb, & Whishaw, 1990).

2. LITERATURE REVIEW

The purely physical sequelae of both moderate and severe head injuries are more likely to be acknowledged by the closed head injured person and the family, but literature is increasingly documenting that often the most serious long term morbidity after CHI, namely, the cognitive, behavioural, social, emotional and family disturbance, is the most problematic for those involved (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Hendryx, 1989; McClelland, 1986).

According to the literature (Brooks et al., 1986; Hendryx, 1980; Prigatano, Altman, & O'Brien, 1990; Rappaport, Herrero, & Rappaport, 1989) the CHI patient under-reported emotional and behavioural problems compared with the problems reported by family members. McKinlay, Brooks, and Bond (1981) interviewed family members of 55 brain injured adults, 3-12 months post injury. The family members were asked to report changes in the person which had become evident after the head injury, and which were present in more recent times. The results indicated that the problems most frequently reported by the relatives were emotional changes (psychological and behavioural). In addition, the family reported these same problem areas 5 years after head injury.

Brooks et al., (1986) attempted to look at the natural history (over a 5 year period) of both the objective and subjective consequences of severe head injury, and to identify what types of burdens were perceived by the family. The

families reported being stressed because of higher levels of emotional and cognitive changes in the patient. Physical changes seemed to be much less prominent. The authors reported that the changes in these areas appeared to be either the same or worse 5 years later compared to that after one year. For the relatives, the situation definitely worsened 5 years post injury because of the psychological changes rather than the physical changes in the head injured person. There is agreement that the psychological sequelae of CHI (emotional and cognitive component) is the most troublesome for the family of the patient (Chisholm, 1987; Gloag, 1985; Humphrey, 1978; Lezak, 1986; McGuire & Greenwood, 1990; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981).

Hendryx (1989) in her longitudinal (questionnaire) study, compared responses of 20 CHI adults with moderate to good recovery (Glascow Coma Outcome Scale), with 20 control subjects and 13 family members. She looked at psychosocial deficits in three areas of functioning, cognitive, emotional and physical. Cognitive changes were rated as more extreme than changes in emotion by the head-injured subjects, whereas estimates of cognitive, emotional or physical changes did not differ significantly in the ratings of family members. Although the physical changes were acknowledged by all the subjects, some other changes were denied. For example, the study indicated that head injured persons admitted cognitive difficulties but denied experiencing any emotional changes, however vice versa was true for family members. Hendryx speculated that denial may be explained by the lack of awareness in these particular areas by both the head-injured adult and family members.. This study however assessed one subgroup of CHI adults, a homogenous sample

with all subjects having a high level of recovery. Therefore the results obtained from this study cannot be generalised to all CHI adults and their families.

Not all researchers have agreed on the relative under-reporting of deficits by the head injured patient (Humphrey, & Uttley, 1978; Kinsella, Moran, & Ford, 1988; Oddy, Tyreman, & Humphrey, 1984). The above authors found that in their studies, reports documented by relatives and the head injured persons were similar in nature. Most head-injured persons recognised and reported the changes that had occurred to them and their posttrauma functioning. Perhaps, the discrepancy noted by the work of these authors, may be accounted by the high number of mild head-injured patients contained in their studies in opposed to moderate and severely head-injured patients.

2.1 Cognitive impairment following closed head injury

After moderate to severe head injury, cognitive deficits are the most common impairment (Brooks, 1990). Cognition includes the use of processes and the knowledge base to, firstly, make decisions as to the most appropriate and functional way of interacting with the environment, secondly, to execute these decisions, thirdly, to monitor responses to determine the appropriateness and accuracy of these decisions and finally, to adjust behaviour, if it is determined to be inappropriate or inaccurate (Adamovich, 1991). A wide variety of deficits in this area have been documented including arousal, disorders of intellect, learning and memory, language, perceptual-motor function, goal selection and planning (Carr, 1993). The consequences of head injury were identified by earlier (pre 1940's) studies, these consequences included learning and memory deficits, disturbance of thinking and complex

perceptual skills, and a slowness in information processing. These claims seemed to have since been confirmed by contemporary studies. In summary, performance, attention, organization, planning, memory, monitoring, flexibility in thinking, perception and sensitivity all come under the cognitive umbrella.

Generally it has been reported that different cognitive functions recovered at differing rates (Lezak, 1983; Lishman, 1988). Overall there is considerable variability in the recovery of the cognitive function, which depends on task complexity and severity of injury. Apparently recovery is more significant six months after the injury than it is prior to the six months (Adamovich, Henderson, & Auerbach, 1985; Smith, 1993).

Lishman (1973), pointed out that other factors beside severity of the head injury can affect cognitive outcome, for example, the time factor. Posttraumatic impairments may show substantial improvements over a period of months. Neuronal repair and recovery is an important factor over the post-recovery phase, whereas acquisitions of lost functions by intact neural networks, improvement in motivation and adjustment can account for significant improvements over the late post-injury period (Lishman, 1973; McClelland, 1986).

In CHI even the less severe cognitive defects are devastating and appear to be among the most serious head injury (Gloag, 1985). For the head-injured persons the cognitive impairment and personality changes seem to be the most debilitating, even more than the physical disability involved. There tends to be general agreement in research that the more severe the initial CHI, the more severe the cognitive impairments (McClelland, 1986). However there is also substantial debate over this relationship, and the relationship between more

detailed quantitative measures of severity is shown to be relatively weak in other studies (Lishman, 1973).

2.1.1. Attention and concentration.

Attention comprises several elements including the speed of information processing, selectivity, and alertness and concentration on a task. References to deficits in attentional processes in closed head-injury (CHI) are numerous (van Zomeren, Brouwer, & Deelman, 1984). After CHI, the manipulation of the focus of attention tends to be impaired in three basic ways (1) initiating and sustaining attention; (2) shifting the focus of attention when appropriate, and (3) inhibiting the inappropriate shifting of the focus of attention (Adamovich, 1991).

There is a growth in literature (Berrol, 1990; Lezak, 1983) documenting attention deficits after head-injury. Attention deficits are reported to be a common impairment and are thought to include a multiplicity of other functions, such as, problem solving, communication, and memory (Smith, 1993). Literature (Lezak, 1983; Smith, 1993) indicates that attentional disorders occur almost invariably after head injury, and although such deficits lessen in severity over the course of recovery, significant deficits are often present many months or years after injury (Smith & Godfrey, 1994). Without the ability to pay attention, a person cannot work productively or even stay involved in a conversation in a social setting. The functions of attention and concentration are both prerequisites for any higher mental task. They set the scene for independent living, career advancement, and even social relationships (Levin, Benton, & Grossman, 1984). Other complications that accompany

attention and concentration deficits are fatigue, an increased need for sleep, easy distractibility, an inability to shift from topic to topic while engaged in conversation, and a lack of focus.

As mentioned above, although attention deficits may show improvement over time, literature is increasingly documenting that significant problems in this area may often be present for a long time, months to years after injury.

2.1.2 Learning and memory problems.

Memory and learning disorders are amongst the most well known cognitive effects of head injury, and seem to trouble most CHI people at some time (Lezak, 1983). Memory problems are thought to be the result of temporal lobe damage (where most memory is stored) or damage to the hippocampus (which is responsible for registering and retrieving information). Naturally a lack of memory will hinder re-entry into the community and studies have shown that approximately 65-70 per cent of head-injured persons could not find work because of memory deficits (Fenelick & Ryan, 1991).

After severe brain injury, disorders in learning and memory occur as a rule and complaints made by patients in this area have typically been collaborated by relatives (Brooks, 1990). The complaints range from trivial to profound forgetfulness, and temporary to permanent amnesia (Brooks, 1990).

Memory deficits can occur due to ineffective encoding of information, inadequate storage of information, difficulty retrieving information using recognition, cued recall or free recall, and a lack of strategies to deal with interferences (Adamovich, 1991). Various types of memory include semantic memory, episodic memory, immediate recall, delayed recall, recall with

interference and long term memory. These types of memories play an important role in an individual's ability to function and to be able to communicate successfully (Adamovich, 1991). Depending on the amount of circumscribed damage that has occurred to the structures in the diencephalon or medial temporal lobe structures, selective memory impairment may result and persist after head-injury despite good restitution of other intellectual functions (Lishman, 1988). Brooks (1975) found short-term memory to be intact in severely injured patients, but found that their long-term memory was significantly worse than the controls in the study. Smith (1993) reported that other studies using matched control groups found that CHI adults demonstrated significantly poorer scores on tests of verbal learning and on selective reminding tasks (Marsh, Knight & Godfrey, 1990).

Patients with moderate to severe head trauma experience numerous difficulties with learning new material (Brooks, 1984). They experience reduced or slow learning which is often compounded by defective information retrieval. These patients are unable to use learned information, even though they have stored the new information (Lezak, 1983).

2.1.3. Higher cognitive/executive functioning

According to literature (Lezak, 1983; Smith, 1993, Struss, & Benson, 1984) both intellectual impairment and executive functioning is relatively common in closed head injury. Closed head-injured individuals have impaired ability to plan, initiate and monitor their activities. They often lack the 'building block' cognitive skills needed to perform executive functioning and cannot understand the abstract, and often fail to follow through or complete a

task (stop half way through performing a task)(Richardson, 1990). They may have difficulty solving problems in a realistic way and deficits in performing sequential tasks and learning from their mistakes and successes. Impairment of executive functions might be a common deficit, but frequently it is not an easy one to accept. One study (Richardson, 1990) found that 90 per cent of head-injured persons suffering from impairment of executive function could not cope with vocational training. However executive functioning has been documented to affect all areas of functioning (Brooks, 1984; Jennett, & Teasdale, 1981; Richardson, 1990), but the information on executive functioning after closed-head injury appears to be mainly descriptive. According to McClelland (1988) intellectual impairment is relatively common, however in opposed some contemporary literature (Marsh, Knight, & Godfrey; Smith 1993) reported that impairment is more prominent on performance tasks and less severe with verbal tasks. However elaboration in this area is difficult because it seems that only a sparse amount of empirical work exists on executive functioning.

Many of the studies of cognitive deficits, after CHI, made the assumption that deficits identified by psychological tests have a major impact on the patient in his everyday life. For example psychological testing has shown the existence of frustration, irritation, depression and disinhibition, which all have cognitive roots, and all may be the result of brain damage (Lezak, 1986).

2.1.4 Information processing:

One of the most common problems reported appear to be the slowness of information processing (Lezak, 1987; Smith, 1993). Speed of mental activity increases but seldom to pre-traumatic levels and remains as one of the major

and basic cognitive handicaps of almost all patients. Symptoms are suggestive of disruption of mediobasal frontal and medial temporal structures (Webster, & Scott, 1983). Deficits of attention may partly explain this general slowing down, which in turn slows down the speed of information processing and sometimes a drop in IQ on some or all the subscales; the other being the impairment of memory which tends to improve a little with time (Lezak, 1983). Mental slowness, as reflected by longer reaction times and deterioration of performance in time-limited tasks, is one of the key characteristics of individuals who survive closed head injuries.

Information processing refers to the analysing and synthesising of information in sequential steps. It has been documented that, quite often, closed head injured individuals lack the skills necessary to process and give order to information. One study (Tromp, & Mulder, 1991) indicated that novelty and not motor complexity, is a discriminating task variable in mental slowness after head injury. This invariably results in difficulty in adapting to and learning from, their environment. Additionally, difficulty arises because of the inability to assimilate and accommodate new information. Assimilation means to interpret objects and events according to a person's current way of thinking and past experiences and accommodation refers to the revision of concepts and opinions based on new information and experience (Adamovich et al., 1985).

2.1.5. Language difficulties

Language problems (aphasia) and communication problems are reported to be evident in only a relatively small proportion of closed head-injured patients.

Apparently it is more likely to occur only in those cases where mass lesions involving the dominant hemisphere have occurred. However subclinical language disturbance (poor verbal memory and impoverished verbal associative fluency) is common after closed head-injury. The prognosis for future recovery from aphasia is generally better in young adults, and persistent language deficits that may occur are commonly associated with general cognitive impairment (Levin et al., 1982).

2.2. Emotional and behavioural impairment following closed head injury

Research results on emotional adjustment following CHI appears to be varied across studies. This may be due, in part, to the problem of methodological inconsistencies, which include the differing assessment devices, variability in samples as well as the transient nature of emotional disturbances (Smith, 1993). However significant emotional changes have been shown to occur over time (Godfrey, Partridge, Knight, & Bishara, 1993). Behavioural problems have been documented to have profound and lasting effects, not only on the individual, but also on close others (Smith, 1993). According to Smith (1993) behavioural disorders can be classified as either positive (excesses) or negative (deficits). Behaviour excesses include irritability, impulsivity and demanding behaviour, verbal aggression and impatience and deficits include, lack of motivation, lack of self care skills and apathy (Smith, 1993). Common behavioural deficits include lack of drive, loss of motivation, apathy and lack of self care skills (Smith, & Godfrey, 1994). Personality change which appears to frequently accompany head injury sequelae was reported by relatives (85%) to

occur and remain in 65% of the cases as long as 10-15 years post injury (Smith, & Godfrey, 1994).

Cognitive deficits have shown to improve following significant craniocerebral trauma and emotional recovery can in some cases parallel these improvements. On the other hand, emotional difficulties may tend to increase as time passes on. Emotional control may be impaired due to the striking of the brain against the frontal portion and under side of the skull. The areas in the front of the brain, which control emotion, may cause bruising or damage which in turn produces a decrease in the person's ability to use the appropriate emotion at the appropriate time to the appropriate degree (Jones, & Lorman, 1988). The ways in which emotional difficulties are experienced post closed head-injury are varied. For example, there may be difficulties in control and regulation of emotional states. The types of emotional change most commonly includes possible silliness, irritability, lability, apathy and increase, decrease, or absence of sexual drive (Bond, 1984). Self-centred behaviour, fatigue, lowered self-esteem, restlessness, an inability to cope and anger are also commonly experienced (Jones, & Lorman, 1988).

Anxiety and depression are also common after head injury (Gloag, 1985; Lezak, 1988; Jones, & Lorman, 1988; McClelland, 1988). These negative mood states may be indirect consequences of CHI and may represent the CHI individual's emotional reaction to the awareness of the disability they are now faced with. Although in some cases these individuals may not fully comprehend the disability, they may nevertheless be aware of the loss of independence, the loss of friends or social network, and the loss of their jobs.

Changes in mood may show certain similarities in many CHI persons during their recovery. Of these, the most noticeable are, increases in irritability and impatience with lowered tolerance for frustration and an increased likelihood of outbursts of temper. In association with this change, suspiciousness and even paranoid delusions may develop.

Previous research have suggested that the more transient disorders may be the result of neurochemical changes in the injured brain while prolonged depressive disorders, on the other hand may have a more complex nature and may occur, either as a result of hemispheric damage or may be reactive to physical or cognitive impairment. According to Lezak (1983) head-injured patients with left hemisphere involvement have been reported to indicate feelings of depression more often than their right hemisphere counterparts. In addition, lesion location was significantly associated with the occurrence of depression, particularly with left dorsolateral frontal and left basal ganglia lesions. This may suggest that organic disturbance plays a large part in the development of depression.

However other research has suggested that as CHI patients develop more insight into the impairments after head-injury therefore emotional disturbances, such as, depression and anxiety inevitably follow. This may suggest that levels of anxiety tend to rise, and depressed mood fluctuates, perhaps in association with periodic insight into the significance of residual disabilities. It was indicated that between 27% and 60% of CHI adults have been classified as being clinically depressed (Smith, 1993), but unlike anxiety, depression in these individuals was no greater than that of matched control groups in the first six months, but appeared to increase two to three years following head injury

(Godfrey, Partridge, Knight, & Bishara, 1993). Fordyce et al (1983) had in previously reported similar results, for example, in their study evaluated patients who were either 6 months postinjury or less postinjury. They found (based on Minnesota Multiphasic Personality Inventory and the Katz Adjustment Scale) that the subjects who were more than 6 months postinjury experienced more anxiety and depression, were more confused and socially withdrawn than the subject who were less than 6 months postinjury. It was suggested that insight and awareness into their disability contributed to this result. Another study (Jorge, Robinson, Arndt, Starkstein, & Sergio, 1993) assessed depression following closed head injury at 3 month intervals up to 12 months follow-up in 66 patients. Of the 66 patients involved, 28 patients met Diagnostic and Statistical Manual of Mental Disorders III-R (DSM-III-R, American Psychological Association, 1987) diagnostic criteria for major depression at some time during the study (17 in the acute stage, 11 during follow-up). In addition, this study indicated that both biological or organic and social/psychological factors (increased awareness of the resulting deficits) play a role in post CHI depression. However most of the subjects involved in this study were primarily young white males with a history of alcohol or drug abuse and came from lower socioeconomic classes, thus making generalisation difficult.

Lezak (1983) reported depression as being common in most CHI adults. Although the severity and duration of the depressive reaction varies greatly among individuals, depending on extraneous factors to the brain condition. In fact she further reported that patients who have experienced no depression as a consequence of head injury, have either lost some capacity for "self-

appreciation" or reality testing, or are simply denying their problems. Depression according to Lezak (1983), and Lishman (1978), is commonly first experienced within the year following brain damage. For some CHI individuals depression may become muted with time, but for others, chronic depression may persist (Lezak, 1983).

The aetiology of depression and other emotional sequelae of head-injury therefore has been attributed to either physiological effects of the brain dysfunction or alternatively, to the patient's perception of the loss they may have encountered, that may make life goals less attainable (Newman & Sweet, 1992; Orsillo, & McCaffrey, 1992).

Premorbid functioning, for example, pre-existing psychopathology, personality type, lack of coping skills, level of intellectual functioning, medical problems may contribute later, that is after head-injury to emotional distress and the development of depression and suicide (Alberts & Binder, 1991). Therefore it would be useful in the treatment of CHI patients to acquire premorbid information from significant others as it may have a marked impact on the focus of therapy and outcome (Alberts et al., 1991).

According to Lezak (1988) and Fordyce et al., (1983), anxiety can also arise as a result of awareness of psychosocial deficits, which can erode the CHI self confidence, for example, anxiety can cause feelings of inadequacy in situations where the individual was competent premorbidly, it can cause confusion, it can cause the individual to become unduly cautious and can create fears of being out of control. Anxiety is typically manifested internally, in that the family may see the patient being withdrawn, easily upset and moody (Lezak, 1988). Although anxiety may appear to be a reaction to the loss of

control the CHI individual may be feeling, it may also present as fearfulness, for example, the individual does not attempt anything new. This may lead to isolation, which in turn may pressure the family members to be constantly present (Lezak, 1988). Anxiety appears to be significantly lower at 2-3 years after head-injury, compared with at six months after head-injury, perhaps implicating the issue of insight.

Insight in many patients usually alternates with periods of denial of disability (Bond, 1984). Emotional behaviours may be due to the brain injury itself or it may be due to the individual's reaction to the change in situation and these may improve as the person recovers (Jones, & Lorman, 1988). Bond (1984) has suggested that emotional dysfunction following CHI may be transient in nature, with the onset at the time when the patients gain some insight into the extent of their disability in all areas particularly cognitively, physically and socially (Fordyce, Roueche, & Prigatano, 1983; Prigatano, 1986) One earlier study (Fordyce et al., 1983) indicated greater emotional dysfunction in chronic head injured patients compared to acute patients suggesting , that unlike cognitive dysfunction, patients with emotional disturbance can worsen with the passage of time. This may be due to the fact that the patient is not aware of residual deficits and problems in social adjustment during the acute phase following trauma (Fordyce et al., 1983). An understanding of the fact that emotional distress worsens with the passage of time may be particularly important and useful in rehabilitation as part of the symptom picture. A more recent study (Godfrey, Partridge, & Knight, 1993) also indicated that, as insight and awareness increases for the closed head-injured person, so does their level of emotional dysfunctional. The

rehabilitation picture must take these aspects into account if these persons are going to substantially improve their quality of life (Fordyce et. al., 1983). However denial may, in contrast to the above psychological interpretation, be a manifestation of an organic deficit, where the head-injured person is simply not aware of their deficits. These organically mediated deficits are described by Lezak (1983) as a loss of self-monitoring which is part of the cognitive sequelae to CHI, or simply a lack of appreciation of the deficits.

Disruption of social skills is another area where the individual with a closed head injury may be disturbed, and this may, in turn, exacerbate depression, anxiety or anger in a CHI individual. It includes the inability to hold a conversation, or the individual may find it difficult not to interrupt a conversation. Inhibiting actions may also be impaired accompanied by impulsive behaviours (Jones, & Lorman, 1988). A recent controlled study (Spence, Godfrey, Knight, & Bishara, 1993) examined social skills in 14 CHI patients who were assessed at four months post injury and compared with control subjects, found that over half of the CHI patients had been classified as socially unskilled. This finding was consistent with other earlier studies (Godfrey, Knight, Marsh, Moroney, Bishara, 1989; Lezak, 1978a; Newton, & Johnson, 1985; Weddell, Oddy, & Jenkins, 1979).

Lezak (1978b) identified a number of factors that may account for social deficiencies in these individuals. Firstly, the fact that these individuals are traumatically removed from their social networks and reintroduced to them after the head injury with dramatic physical and cognitive deficits. Secondly, the most common problem of distractibility may disrupt social interaction.

Finally there is the problem of both physical and mental fatigue, which seems to go hand in hand with head injury (McMorrow, Lloyd, & Fralish, 1986).

2.3. Physical impairment following closed head injury

From perusing research in the closed head-injury area, it seems evident that the physical sequelae of head injury is far less prominent and is seen as being far less serious, compared to the emotional, behavioural and cognitive sequelae of closed head-injury. The physical problems following closed head injury include epileptic seizures, loss of motor control and coordination, sensory problems, speaking and swallowing disorders, fatigue and headaches. Each of these are briefly elaborated below:

Epilepsy is an identified physical problem which develops as a result of the head injury (Carr, 1993). However it affects 5% of people with a closed head-injury and 30% when the dura mater has been penetrated, for example, the highest incidence reported was from wounds in the central regions of the brain (parietal 65%, motor and pre-motor cortex 55%, with the diminished incidence towards the poles (pre-frontal 39%, temporal 38%, occipital 38%) (Lishman, 1988). According to Lezak (1983), epileptic patients are more prone to personality changes. Epileptic seizures come in several different types, such as, generalized or grand mal seizures, focal or partial seizures. Patients with generalised seizures tend to have greater reported deficits in other areas of functioning, for example, cognitive deficits (Lezak, 1983).

Following head injury a loss of motor control and coordination may occur such as, paralysis of the right or left hand side of the body; ataxia and

uncoordinated, unbalanced and awkward muscle movements and the loss of fine and/or gross motor dexterity. For example, a person who could once knit can no longer hold knitting needles because of the lack of agility and dexterity in their fingers (Carr, 1993; Fenelick, & Ryan, 1991). These impairments may produce obstacles to the CHI person as far as vocational and recreational pursuits are concerned, and may also place a major burden on those who are in a caretaking role of CHI individuals(Lezak, 1986).

Loss of stamina and endurance become common problems because of the lack of energy affecting the individual's performance in all areas of daily life (Carr, 1993). Fatigue and headaches therefore affect nearly every head injured person at one time or another (Fenelick, & Ryan, 1991). The cause of these complaints have been documented to occur as a result of diffuse damage that accompanies brain damage which may consist of minute lesions and lacerations, which may be scattered throughout the brain substance and that may eventually become the sites of degenerative changes or scar tissue or simply little cavities. This type of damage tends to compromise other areas of functioning such as mental speed, attentional functions, cognitive efficiency and in severe head-injury many high level functions, which in turn causes many complaints of which one of them is fatigue (Lezak, 1983). This process (fatigue and lack of stamina) may in turn interfere with rehabilitation efforts, which highlights the seriousness of this type of complaint.

Sensory perceptions are a products of both cognitive and physical abilities (Lezak, 1983). Common physical deficits include cranial nerve lesions such as anosmia, oculomotor pareses, and visual field defects etc. The severity of visual loss could range from diminished acuity to complete blindness (Levin,

1982) These deficits can occur as a result of damage to the brain as well as damage to the sensory receptive organs affecting the individual's capability to taste, smell, hear, see and touch. For example, damage to the occipital lobe can cause blindness and sometimes *diplopia* or double vision which occurs as a result of cranial nerve (trochlear or oculomotor nerves) damage or muscle imbalance (Fenelick, & Ryan, 1991). Sensitivity in the visual fields (optic nerve), in the mouth (glossopharyngeal nerve, taste is totally lost), anosmia (damage to the olfactory nerve, loss of sense of smell) as well as deficits in auditory perception (auditory vestibular nerve, inability to hear sounds), and problems in tactile response (trigeminal nerve, decreased sensitivity to pain, temperature and texture) may all be part of the physical sequelae of closed head-injury (Lezak, 1983).

Speaking and swallowing disorders can also occur as a result of damage to a cranial nerve(vagus nerve). Difficulties that arise could be in a condition termed *dysarthria* (speech is extremely slurred, slower or quieter than normal). Comparisons of communication disorders, (between the CHI individual and individuals with an open wound) have been discussed (Gropher, 1984). This information indicated that persons with a CHI have fewer communication deficits as a group, than did the penetrating-wound persons and that these persons also improved in this area at a faster rate. Gropher (1984) indicated the prevalence of communication disorders following CHI to be in the 15 to 25 per cent range. However with the passage of time individuals with CHI may only have mild effects of dysarthria. Another condition (relatively rare for CHI) that can exist is called *dysphagia* (inability to chew or swallow) can cause

major problems in malnutrition, the sufferer is typically fed through a feeding tube (Fenelick, & Ryan, 1991).

Loss of bladder and bowel control, which may have a cognitive component, for example, the CHI adult may not be able to process or be aware of the need to go to the toilet at the time of need, has been described as a very unnerving physical disability. The head injured individual could have problems urinating, requiring intermittent catherization or may suffer incontinence (Fenelick, & Ryan, 1991).

In conclusion, physical impairments as described above and spasticity or isolated cranial nerve lesions tend to generally improve over a period of months, and although the extend of the recovery depends on individual differences, these impairments seldom result in significant handicap (McClelland, 1986). However mental impairment is far more significant and far more enduring and contributes most to chronic disability and handicap (Jennett & Bond, 1975). Mental and Physical impairment most invariably co-exist, nevertheless, and often compound total disability.

2.4. Vocational adjustment

While some studies have shown that the majority of patients with a CHI to return to work, this depends vastly on the severity of the injury. The patients with prolonged periods of PTA (Post-Traumatic Amnesia) or unconsciousness fail to return to work (Oddy, Humphrey, & Uttley, 1978; Rappaport et al., 1989) In addition, those that do return to work often have to accept jobs with reduced satisfaction and considerably reduced responsibility (McClelland, 1986; Rappaport et al., 1989). McClelland stated that age is often the deciding

factor as to who can successfully return to work, and the younger the person, most commonly, the more successful. However predicting vocational outcome for this population can prove to be difficult because of the complexity, diffuseness and uniqueness of each injury (Bullard, & Cutshaw, 1991). Psychosocial difficulties relating to social and emotional symptoms such as aggression, depression, anxiety, impulsivity, immaturity, obsessional behaviours, mood swings, egocentricity and disinhibition may in turn exacerbate the inability of the individual to be able to be employable and relate to others in work related environments (Carr, 1993).

McClelland (1986) suggested family relationships were also consequential in vocational adjustment, for example, some head injured persons may have problems adjusting to their family responsibilities, on the other hand, the family of the head injured person may not be able to cope with the high burden and stress that they are faced with. This lack of adjustment by both parties involved often causes marital breakups, making vocational adjustment even more difficult (Bond, 1975). Due to frequent marriage separations the head-injured person is often faced with major life and role changes, and many report loneliness and isolation, thus making vocational adjustment difficult (McClelland, 1986).

Another important factor highlighted (Carr, 1993; Oddy et al., 1978) was the lack of service provisions (a service set-up to assist the head-injured person to return to work), especially for the head-injured individuals in need of additional support. Families may find it increasingly difficult to encourage the head-injured person to return to work without a service provision to help the individual adjust to the demands of a working environment (Oddy et al., 1978).

Rappaport et al., (1989) in their study pointed out that because of the lack of employability, welfare dependency (disability allowance and social security payments) from 0% pretrauma, was as high as 87% posttrauma, at 10 years follow-up

Carr (1993) in a survey, which was conducted nationally in New Zealand, reported a general dissatisfaction amongst all head-injured persons and their families with intervention for vocational rehabilitation. This may be due to the inability for services to recognise the varied and complex needs of each head-injured individual. Most head-injuries are heterogeneous and therefore people have a varied rate at which they are able to contemplate returning to work. However, consumers and their families found that services throughout New Zealand placed a high expectation on the appropriate timing of vocational rehabilitation (Carr, 1993). Most individuals in Carr's survey felt that realistic goals should be set by the interventions offered. For example, goals that are predetermined by professionals in this area, such as neuropsychologists who could offer regular assessments and for occupational therapists who should offer realistic and practical assessments. Carr also highlighted the need for placing high priority on supported work programmes (on-site employment specialist), particularly for those who are unlikely to gain full time employment but feel the need to have a supported working environment.

Researchers have (Brooks et al., 1987; Wehman, Kreutzer, West, Sherron, Zasler, Groah, Stonnington, Burns, & Sale, 1990) stated that the unemployment rate of the head-injured population, especially severely head injured, to be anywhere from 60-80%. Wehman et al. (1990), in their study showed that from 91% of individuals who were competitively employed pre

head injury, only 36% retained these jobs. With supported employment (on-site employment specialist) of the 41 people placed in this situation , 71% still continued to work which added some optimism regarding vocation for the head injured individual.

In general, poor prognostic indicators regarding the closed head injured person's likelihood to return to the work force appear to be increased age; longer posttraumatic amnesia; previous personality deficits such as alcoholism and emotional problems; gross physical handicaps; lower premorbid intelligence; the lack of professional training or higher education pre-morbidity; non-supportive employers; and premorbid jobs that require speed, safety, and efficiency; and low motivation (Adamovich et al., 1985). Motivation problems seem to arise when the closed head injured person receives little gratification from work when they are only capable of doing simpler, non-demanding jobs following their accidents. The denial process experienced by most head injured persons may also interfere with their willingness to accept lower level positions which may mean lower pay (Adamonvich et al., 1985). Generally it appears, especially from a recent New Zealand study (Carr, 1993) that in this country there is a serious lack of facilities and services for the head-injured person at all levels.

2.5 Family issues

Research confirms the debilitating effects on both the CHI individuals and their families following closed head-injury. Closed head injury can affect the patient's personal, interpersonal and societal systems (Brooks, 1991; Dufour, Chappel-Aiken, & Gueldner, 1992; Lezak, 1978, 1988) but the patients do not

suffer alone. It is well documented that families can also experience the impact of the injury for many years. The cognitive, behavioural, physical and emotional effects of a CHI add to the burden placed on these families (Dufour et al., 1992). There have been rare exceptions of the consequences of head injury for the family, for example, the head-injured individual has changed for the better (positive personality changes have occurred after head-injury) and as a result, the family may be much happier, but unfortunately these are rare exceptions (Brooks, 1991).

Relatives and head-injured individuals often have widely different perspectives about the nature and amount of dysfunction following head injury, which appear to have some consequences for psychosocial adjustment and treatment (Brooks, & McKinlay, 1983). A study (Fordyce, & Roueche, 1983) reviewed changes in perspectives of relatives, rehabilitation staff and family members. This study included 28 severely injured patients who were consecutive participants in a neuropsychological rehabilitation program. In general, the CHI patients rated themselves as having the least behavioural impairment, especially compared to staff members. Relatives, on the other hand, were unaware of cognitive limitations of the patients which lead to enhanced competency reports in the cognitive area of functioning.

The whole area of family issues regarding closed head injury appears to be widely documented. Family distress following head injury has been well noted (Bergland, & Thomas, 1991; Brooks, 1991; Carr, 1993; Dufour, Aiken, & Gueldner, 1992; Lezak, 1988; Smith, 1993). The effects of brain injury are not limited to the individual as noted above, in most cases they are suffered by both the victims and their families (Sumners, 1994). This statement has serious

implications as far as treatment outcome is concerned. The family can be regarded as a therapeutic resource, and if their needs are not met in the treatment process, they could hinder success for the head injured individual (Sumners, 1994). Therefore the success of rehabilitation may centre on, not just the attitudes of the head injured patient, but also the quality and amount of family support available (Quine, Pierce, & Lyle, 1988; Wood, 1989). It appears crucial that the family's cooperation and participation to the rehabilitation of the closed head injured person is increased (Johnson & Higgins, 1987).

A longitudinal study (Smith, 1993), demonstrated the long term effectiveness of family based treatments in helping families affected by head injury to emotionally adjust to their situation. The results supported treatments (family based interventions) targeted at both the CHI individual and the family from the very beginning, when head-injury occurs. Smith (1993) saw family involvement in the rehabilitation process of head-injury to be crucial and emphasized the role of psychotherapy in most cases.

Each family may differ in the way they deal with the problems associated with having a head injured member, this difference may be due to premorbid cohesiveness, the family's social support systems, the family's attitudes about illness, responsibility and financial supports etc (Lezak, 1988). However Lezak (1988) suggested the fact that a lot of the problems presented by the CHI individual may be quite subtle, which makes it difficult for the typical family member, who has not prepared or has had little if any experience with such psychological matters to handle the situation before them. On the other hand,

in order for the CHI person to adapt to the new situation, the person may have to make internal and external changes (Florian, Katz, & Lahav, 1991).

To a lesser or greater degree, the CHI person becomes dependent on family members. Due to the nature of brain injury, changes in personality and behaviour are common. The CHI person may become inflexible and often use primitive defense mechanisms which may prevent the person from gaining real insight into their new situation. In order to make progress, head injured individuals may need to match their pre-injury self-image to the new reality (Florian et al., 1991). The family may be the primary support and vehicle in providing necessary assistance for that CHI individual to cope with this reality (Florian et al., 1991)

According to Rape, Bush, and Slavin (1992), several authors have developed stage models to conceptualise the family's response to a head-injured member. The first stage postulated is *initial shock response* following the injury where helplessness, worry and apprehension are the primary characteristics. The second stage is one of *emotional relief* where they learn that their head injured family member will survive, which may be followed by a minimisation of the injured member's deficits and unrealistic expectations may set-in regarding full recovery of premorbid activities etc. Within 3 to 24 months other stages develop, such as *acknowledgment of permanent deficits and emotional turmoil, bargaining, mourning or working through, acceptance and restructuring* (Rape et al., 1991). The acceptance and restructuring phase according to Lezak (1986) is where the family become emotionally detached from the head-injured person and divorce, separation or family estrangement are not uncommon forms of restructuring

Some literature (Florian et al., 1989; Lezak, 1988; Rosenbaum, & Najensen, 1976) have compared and documented the reactions of family members to their head-injured member. However the Rosenbaum et al. (1976) study restricts its generalisation as it was carried out on soldiers who received their injuries in battle and included a small sample (n=10). It was suggested that wives of CHI experienced more difficulties with the impact of the injury than other members of the family. The wives found it difficult to cope with losing their primary companion, emotional and sometimes social and financial support person. The spouse's feelings of responsibility and fear of social rejection may stop them from considering a divorce. The wives tend to lose their social contacts as they no longer may have a partner who can enjoy social activities, in addition, they may have lost the intimacy they shared pre-injury with the CHI partner, which may leave them feeling frustrated and distressed (Rosenbaum, & Najenson, 1976). On the other hand, the mothers of the CHI persons find it easier to accept these changes as they can cope with childish dependent behaviours as dependency once was a part of the relationship they shared (Florian et al., 1989; Lezak, 1988). Thus the problems of childishness are familiar to the mothers, but are a new feature for the wives, which means that a total role shift may have occurred for the wives (from partner to carer) however this may not be the case for the mother (Brooks, 1991).

Nevertheless marital conflicts have been indicated to occur between the parents of the CHI person (Lezak, 1988). For example, the father feels rejected by the mother of the head-injured person, and the mother's focus shifts to or more time is spent with the head-injured individual. Therefore it is not unusual for marriages to dissolve in this situation. Parents that do survive the

turmoil of having an head-injured member may not be able to live their own lives and may face added financial responsibility (Lezak, 1988).

Within the family structure, the other family members, besides the parents or wives, may also experience distress. These members being the children or siblings of the CHI person. They also suffer from having to live with a different person but with the same face. For example, the head-injured parent now has to be cared for and may have become totally dependent on the other parent. This may cause a sharp reduction in parental attention and security for the children, and family times (outings) that the family once shared (Lezak, 1988).

All family members (especially those in a caretaking role) may, during the sequelae of CHI, feel trapped. The immediate family can feel a sense of isolation and abandonment because they can no longer keep up the social contacts, perhaps in fear of the head-injured's inappropriate behaviour on past social occasions. Family needs can become submerged into the needs of the CHI person. They may find it easier to stay at home, therefore becoming isolated (Lezak, 1978).

Investigators (Florian et al., 1991; Lezak, 1988) claimed that long term depression is not uncommon among family members during the earlier phases of head injury. Lezak (1978, 1986, 1988) reported that all family members suffered from depression, which is a natural and expected path, as a reaction to the emotional burden of caring for the head injured person and to the mood fluctuations that the head injured may experience. Caretakers may lose the will to live, become suicidal or turn to alcohol or drugs for comfort (Lezak, 1978).

A suggestion was made that denial instead of depression may occur for some family members (Lezak, 1976; Rape et al., 1991). Lezak (1978) felt

denial to be related to the unrealistic expectations that family members may have concerning improvements in their injured member. For example, the family members denied any history of the head injury and saw improvements where there were none present.

Needs of the family members have been identified by Dufour et al., (1992). The families share a number of common needs, the one need frequently documented is *the need for information* regarding the changes that might occur in the CHI individual. Another need identified by family members included the need for a consistent, reliable avenue for obtaining information regarding their head-injured member. For example, the need to have a primary informant who can have daily contact with the family keeping them informed of the daily progress or otherwise of the head-injured person. This may help the family feel that they have a sense of control over their situation (Dufour et al., 1992). Other needs included the need for the families to feel that there is hope for some recovery and the need to sense that clinicians dealing with the patient care about that patient. Families expressed the need to feel as though they were part of the health care team or rehabilitation process (Dufour et al., 1992).

In summary it is evident that families can be critical in the rehabilitation process by providing support especially for the moderate to severely head-injured person. By involving relatives, results could be obtained on account of bonding which exists with its injured member, which may motivate the patient and elicit desired responses which could lead to maximise progress (Quine et al., 1988). Professional help for the family in terms of education, counselling

and support could further optimise the situation for all those involved (Dufour et al., 1992; Lezak, 1988; Smith, 1993).

2.6 Methodological limitations

The above studies of the CHI adults and their families are limited in that they do not include a representative sample of patients suffering both moderate to severe head injuries. In most cases the sample has been selected from a rehabilitation institution or similar, biasing the results obtained as a result of using a homogeneous sample. Therefore the results from these studies cannot be generalised, as they may not have epidemiological implications concerning the prevalence of problems in a representative sample of survivors of CHI.

Other methodological problems include, small sample sizes, which may also restrict generalisability. Descriptive or qualitative studies, in some instances, have relied on only one source of information, namely the injured patients, who may be unaware of their deficits, which may lead to under-reporting of the deficits as experienced by the head-injured person. These studies often had variations in the severity of head-injury amongst the subjects, which may cause a discrepancy between two authors studying similar variables. For example, one researcher may have a high proportion of moderate or mildly injured patients who are more likely to be aware of their disabilities, whilst the same is not always true for the severely head-injured.

Another methodological problem concerns the procedures used to identify the CHI adult and family consequences. Most researchers appear to have used their own structured or semi-structures interviews or questionnaires, which may have been designed to look at specific problems associated with head

injury. This raises all the common psychometric problems of reliability, validity and once again generalisability. However, it is difficult to think of alternatives in this broad and heterogeneous population.

Although many studies reviewed here had used control groups, the sample numbers were low. Some control groups did not appear to be appropriate. For example they were not drawn from similar at-risk populations, such as, spinal cord injury or paraplegia, and did not suffer diffuse disabilities as is frequently the case with closed head-injuries (Brooks, 1991).

The methodological criticisms made are not intended to deny the value of the studies within this broad topic of closed head injury. While a more rigorous methodology would allow more firm conclusions to be made, the value of the studies have prompted further much needed research in this developing area of enquiry.

2.7. Conclusions

Closed head injury has frequently been called the ***silent*** injury by people who suffer from its effects. The closed head injured person in most cases does not change in terms of appearance, he or she looks the same, as if, nothing has happened. The impairments suffered, in other words, are invisible (Smith, 1993). Most of the studies in this area are exploratory rather than explanatory, as a general understanding of this topic appears to only have recently emerged. Although there are gaps in literature, a wide range of issues concerning the head-injured individual have been investigated (not all included in this review). Studies have revealed that the effects of closed head injury may be long-lasting and have long-term consequences for both the CHI adults and their families. A

high proportion of CHI individuals experience significant deficits in the important areas of functioning as illustrated above, such as, cognitive, physical, behavioural and emotional deficits. These deficits have been shown to, in turn, affect other areas of functioning for the head-injured individual, such as, vocational adjustment, that is, returning to work, and family issues, such as, adjusting to family life (Gordon, & Hibbard, 1992). However those faced with the task of caring and living with the characterologically altered head injured individual, often referred to as the "head-injured family', could have the most difficult tasks ahead of them, making them vulnerable to emotional stresses (Florian et al., 1991). Therefore, the readjustment process to closed head injury, has to be made by both the individual and the family. Perceptional or qualitative differences opposed to quantitative differences, as far as the degree of deficits encountered in each of the areas described above, namely, cognitive, physical, behavioural and emotional, may exist, making this readjustment process even more challenging for all those involved.

3. RATIONALE AND AIMS OF PRESENT STUDY

The principal aim of the present study was to solicit consumer opinion as opposed to professional opinion, in respect to CHI in the Canterbury area, New Zealand, as most literature in this area is from the United States. New Zealand literature could be useful in generalising findings to the said population, and the information obtained may be useful for mental health professionals working with closed head injured patients. The present study although similar to earlier studies (Brooks, 1986; Hendryx, 1989), for example, it made direct comparisons of perceived changes between families and closed head injured

adults in certain areas of functioning, differed in that it targeted individuals post two years of closed head injury. Like other studies, vocational changes pre and post CHI were also explored. However, unlike the above studies, a semi-structured interview style was utilised. This was particularly useful in establishing rapport with the subject, in pursuing clarification of points made by the subject, in gathering more accurate information without ambiguity, and useful additional information was also gained. In addition, unlike the other studies, the present study incorporated the use of standardised clinical scales to increase reliability in comparing the current functioning with past known functioning of the head-injured subject (as reported by subjects and confirmed by a family member in most cases).

The aims of this study are exploratory rather than explanatory. Because there has been little research on this topic conducted in the New Zealand, this study aims to provide a base for future research, and to raise questions regarding the implications of the possible perceptual differences between the head-injured individuals and their families, as far as deficits of functioning are concerned.

3.1 Hypotheses

A number of hypotheses were investigated in this study on how the subjects and their families would differ in their perceptions of deficits in the areas studied (cognitive, physical, emotional and behavioural). One main relationships was hypothesised.

(1) Direct comparisons of perceived changes between families and closed head injured adults will indicate differences in perception between the closed head-injured adults and that of family members. Also:

(a) that more of the family members will tend to rate negative changes, particularly in the behavioural area than the closed head injured adults.

(b) That physical changes after head-injury will be expected to be perceived similarly by family members and head injured adults.

(c) That negative cognitive changes will be rated by more of the head-injured subjects than the family members.

(d) That the scores of the CHI adults obtained from the clinical scales will indicate depression, anxiety and anger-control problems at the time of testing.

(e) That both family members and head-injured adults will perceive changes (negatively) in employment status of the head-injured adult, after CHI.

CHAPTER TWO

METHOD

This descriptive study allowed for the analysis of psychosocial factors related to closed head injury, specifically participants and family perceptions of changes post trauma. The study was designed to assess the relative importance of these changes in four areas of functioning, cognitive, emotional, behavioural and physical changes, in particular the changes taken by perceptions of families and head injured persons two years after a closed head injury. Vocational status pretrauma and posttrauma were also compared.

In line with other authors (Brooks et al., 1986; Chisholm, 1987; Gloag, 1985; Hendryx, 1989; Humphrey, 1978; Lezak, 1986; McGuire et al., 1990; McKinlay et al., 1981; Prigatano et al., 1990; Rappaport et al., 1989), it was predicted that the changes after head injury would be perceived differentially by the head-injured participants and their families. Behavioural problems were expected to be of more concern to families than to the head injured participants studied, and cognitive difficulties were expected to be more concern to the head injured participants than to the family members. However physical changes post head- injury were expected to be perceived similarly by both the family members and the head injured participants. In addition, the CHI group were expected to have elevated scores in comparison to the standardisation sample in the three clinical scales (Beck Depression Inventory (BDI), State-Trait Anxiety Scale (STAI), State-Trait Anger Expression Inventory (STAXI)) used in this study. For example, the participants

would report symptoms of depression, anxiety and anger at the time of testing. Both groups (CHI subjects and family members) were predicted to perceive employment changes negatively.

1. Participants

Participants were recruited after ethical approval for this research to be undertaken was granted by the Human Ethics Committee, University of Canterbury. All participants gave written, informed consent prior to participation in this study. They were given an information sheet which outlined the purpose of the study, what was required from the participant, and giving an assurance of confidentiality (appendices 1 and 2). The participants were assured that they could withdraw from the study at any time without recrimination should the interview cause discomfort and/or pain.

Eighteen head injured adults (13 male and 5 female) and 10 family members were involved in the present study. The age of the head-injured subjects ranged from 23 to 64 years. The participants were volunteers who replied to requests for participants through two sources. The first source was through the Head Injury Society, Canterbury, New Zealand. The second source was through the media, namely the local newspaper, "The Press" in Christchurch, Canterbury, New Zealand (appendix 14), and through an interview of the experimenter on 'Plains FM' (local radio station) in Christchurch .

Head injured individuals who could be rated as moderate to very severely injured according to the approximate estimates of the PTA (Duration of Post

Traumatic Amnesia) criteria were selected for study. This classification is based on the time between the head injury and the return of continuous memory for everyday events (e.g. who visited yesterday, what was eaten for tea etc.). A head injury is moderate when the length of PTA is longer than 1 hour (between 1 to 24 hours) and is severe when the length of PTA is longer than a day (between 1 to 7 days). The relationship between severity of injury and length of PTA is presented in appendix 15. The PTA information was provided by either the head-injured subject or their family.

The ratio of men to women in the head injured group was 2.6:1. Participants in the head-injured group had sustained a close head injury two or more years ago, and had a coma duration greater than one hour. Where the head-injured participants (n=8) were solicited from the Head Injury Society, according to this organisation, these participants did not exhibit premorbid or primary psychiatric disturbance. The self-referred (n=10) participants (through the media), according to self-reports also did not suffer primary or premorbid psychiatric disturbance.

Ten family members were involved in the present study. Of the ten, six were mothers and four were wives of the head-injured persons.

2. Materials

2.1. Questionnaires

The personal data questionnaire (Part A of the questionnaire, appendix 3) aimed to retrieve biographical information, education, employment and relationship

statuses, pre and post head injury, in order to assess the impact of injury that had occurred in the head injured adult's personal circumstances.

Part B (appendix 4)of the questionnaire requested information on the details of the head injury in order to ascertain the PTA classification, and type of head injury. Whether the participants (head injured and family members) were given information regarding major areas of impairments was also requested in order to discuss treatment implications below.

Part C (appendices 5, 6 & 7) of the questionnaire comprised of three scales: The closed head injury cognitive scale, the closed head injury physical scale and the head injury behavioural scale.

Part D (appendices 8, 9, & 10) of the questionnaire comprised of the emotional scale which was comprised of three standardised scales, namely the Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory (STAI), and the State-Trait Anger Expression Inventory (STAXI). More information on all the above scales is elaborated on below.

2.2. Closed Head Injury Cognitive Scale.

A Cognitive Scale devised by the experimenter was developed by reviewing literature and by using interview questionnaires that Levin's group (1982) described as useful in assessing the sequelae of head injury. Modifications included a more open-ended approach, with examples provided for clarification of the questions asked, when needed, and discussion from the participant on each item was invited. Some suggestions regarding the inclusion of items for this scale were also utilised from a workshop booklet (Smith & Godfrey, 1994). The scale

contained questions on each of the following: Memory, thought processing, concentration, distraction, higher cognitive processes and verbal fluency. This scale included 16 items.

2.3 Closed Head Injury Physical Scale.

The Physical Scale was also devised by the experimenter in the same way as the cognitive scale (details above). The Physical Scale included items on sensory and motor problems, for example, items included the five senses: auditory functioning, tactile functioning, visuo-spatial functioning, the sense of smell and taste, and motor functioning. Once again the items were open-ended, inviting the participant to discuss or offer any additional information that may have been omitted from the scales (cognitive and physical scales). This scale included 11 items.

2.4 Head Injury Behavioural Scale.

The Head injury Behavioural Scale (Godfrey, 1994), consisted of two versions. The first version was to be completed by the head injured adult and the second to be completed by a family member (appendix 7). Each version came with biographical details and instructions on procedure. Both scales (individual's and family's) included 20 items, an option was included to indicate if any of the behaviours had caused distress to the participant, and if so, it provided a scale for rating the intensity of distress the said problem had caused the participant (if any) from 1 to 4, 1 being no distress to 4 being severe distress.

2.5. Standardised Tests.

The last section Part D (appendices 8, 9, & 10) of the questionnaire consisted of three self-report measures which consisted of standardised scales. These were: Beck Depression Inventory, (BDI); State Trait Anxiety Inventory, (STAI-YI and STAI-Y2); and the State Trait Anger Expression Inventory (STAXI) that were completed by the head-injured participants only.

Beck Depression Inventory (BDI) (Beck, Rush, Shaw, & Emery, 1979) was used in the present study because it is one of the most widely used instruments to measure depression in both clinically diagnosed and in normal populations, thus enhancing the comparability of results. In this study it was used as a screening device for depression. It is useful in measuring the severity or intensity of depression in adults and adolescents, rather than as a sole means of diagnosis. It demonstrates high reliability and validity (Beck, Steer, & Garbin, 1988). The revised BDI (Beck, & Emery, 1984; Beck, Rush, Shaw, & Emery, 1979) is a 21 self-report instrument, in multiple choice format.. More particularly, it assesses the presence and severity of affective, cognitive, motivational, and vegetative components of depression. Each item represents a depressive symptom or attitude, such as guilt feelings, social withdrawal or loss of appetite. Each of the 21 symptoms is composed of four statements rated from 0 to 3 in increasing levels of intensity.

The use of the BDI in over 1,000 published research studies has enabled researchers to assess its psychometric properties in various populations (Beck, et al., 1988). For example, Beck et al. (1988), in a review of literature, calculated

mean scores of reliability and validity of this scale. The reported mean coefficient alphas for psychiatric patients and non-psychiatric populations are both in the .80s ($r = 0.86$ and $r = 0.81$ respectively. Concurrent and convergent validity of the BDI has been established with regard to clinical ratings and the Hamilton Psychiatric Rating Scale for Depression (HRSD). For psychiatric patients the mean correlation of the BDI with clinical ratings was 0.72, for non-psychiatric patients the mean correlation was 0.60. The mean correlation of the BDI with the HRSD for psychiatric patients was 0.73, and 0.74 for non-psychiatric subjects (Beck, et al., 1988).

State-Trait Anxiety Inventory (STAI), (Speilberger, Gorsuch, & Lushene (1970), is one of the most widely used self-report measures of subjective anxiety, consisted of 40 brief items, 20 items (A-State scale) required the subjects to report their feelings of anxiousness at the time when they are completing the questionnaire, and 20 items (A-Trait scale) asked the subjects to record how they *generally* feel. Items are presented in substantively counterbalanced order relative to anxiety. Both the A-State and A-Trait scales are used extensively in clinical practice for either a screening of anxiety level or where an ongoing monitor of anxiousness is needed. In the present study both the scales were used in an attempt to screen the level of anxiety in the head-injured individual at the time of testing and also as a means of comparison of anxiety pre and post injury. The participants were instructed to consider each statement from both scales and circle the appropriate answer which increased in intensity from 1 to 4,1 being 'not at all' to 4 being 'very much so'. High estimates of reliability based on internal

consistency statistics were found for both scales (Knight, Hendrika, Waal-Manning, & Spears, 1983). For example, the values of alpha were high for both the A-State and A-Trait scales, being 0.93 and 0.87 respectively This indicated a satisfactory level of scale homogeneity.

State Trait Anger Expression Scale (Staxi), (Spielberger, 1988), provides a measure of experienced and expression of anger. It conceptualises anger in three major components,. the first component, *state anger*, also defined as an emotional state marked by subjective feelings that vary in intensity, and generally accompanied by muscular tension and arousal of the autonomic nervous system. The second component, *trait anger*, is a disposition to perceive a wide range of situations as annoying or frustrating and a tendency to respond to such situations with more frequent elevations of state anger. The Staxi provided a total of 44 statements that people use to describe themselves. The third component, *Anger expression* has three sub-components. The first sub-component involves the *expression of anger* towards others or objects in the environment, also known as *Anger-out*. The second sub-component of anger expression is when anger is directed inward or suppressed, also known as *Anger-in*. The last sub-component of anger expression is known as *Anger control*, where the person makes an attempt to control the expression of anger.

The STAXI consists of 44 items which form six scales and two subscales. The first subscale (State-Anger)comprises a 10-item scale which measures the intensity of angry feelings at a particular time. The second subscale (Trait-Anger) is also a 10-item subscale which measures individual differences in the disposition

to experience anger. Under the 'Trait-Anger' scale are two smaller 4-item subscales which measures a person's general propensity to not only experience anger but to do this without provocation. The second 4-item subscale measures individual differences in the disposition to express anger when criticised. 'Anger-in' is a 8-item scale, 'Anger-out' and 'Anger-control' are also 8-item scales which measures the frequency with which angry feelings are held or suppressed. The rating scales provided 4 options of with increasing levels of intensity from 1 to 4, 1 being 'not at all' to 4 being 'very much so'. The alpha coefficients for the Trait-Anger scale was $r = 0.87$ for both sexes, indicating a high level of internal consistency, and for the State-Anger scale was $r = 0.93$ again for both sexes, providing further evidence of internal consistency of these sub-scales.

2.6. The Interview Questions.

The interview was constructed by the experimenter to gather data regarding perceptions of both the head-injured and their families in four areas of functioning: cognitive, physical, behavioural and emotional as described above, as well as making enquiries regarding vocational and family disturbances. In addition, both groups were invited to comment about the availability of facilities for rehabilitation. They were further invited to comment upon what would have been useful over the sequelae of the CHI for them, and what would be useful for future CHI victims and their families.

Head injured subjects completed a questionnaire (Parts A,B,C, and D) in a semi-structured interview setting with only the subject and the experimenter being present. Because of the exploratory nature of this topic and the individuality of

experience regarding personal loss, partially structured interviews were favoured rather than formally structured interviews. In a partially structured interview the interviewer asks the predetermined questions, in this situation, by providing examples, but retains flexibility by asking follow-up questions Formal interviews, however, are orally administered questionnaires, where the interviewer only provides instructions and records responses (Dane, 1990). The use of open-ended questions allowed participants to raise relevant issues and concerns that may have been overlooked by focused or structured interview questions. A review of the literature suggested areas to investigate regarding the deficits that were studied in the present study.

3. Procedure

The procedure of the study and the approximate time required was explained to each individual on the initial contact by telephone. All the head-injured participants that were contacted fitted the criteria for the study (primarily suffered a closed head-injury of a moderate to severe nature) and were keen to participate as were the family members. Testing took place either at the home of the participant or at the home of the experimenter, whichever was the most convenient and comfortable for the participant. The head-injured participants (individually) rated changes, with a semi-structured focus, in the four areas of functioning, namely, cognitive, physical, behavioural and emotional and compared changes from before and after the injury, with the time of testing as the comparison point after the injury. Family members (individually) rated their perceptions of change in

the head-injured participants after injury, using the same semi-structured interview situation. The family members' answered the same items as the head-injured participant, but without prior knowledge of the head-injured participant's responses. The family members' completed their testing either before or after the head-injured participant, separately.

The testing took approximately 2 to 3 hours for the head-injured participants and a lesser time for the families, depending on individual needs that were respectively accommodated, for instance, having a 15 minute break mid way through the interview, or having 10 minute breaks during the interview and so forth.

CHAPTER THREE

RESULTS

1. TREATMENT OF DATA

The transcribed interviews of the physical and cognitive closed head injury scales were coded into categories and the content analysed by the researcher (see appendices 12 & 13 for the coding schedules). The coding schedules enabled the interview transcripts to be transformed into percentages and tabulated into tables and figures below. The standardised scales (Beck Depression Inventory [BDI]; State Trait Anxiety Scale [STAI]; State Trait Anger Expression Scale [STAXI]) were scored using standardised data and this data was transferred to tables and figures below. The behavioural scale was converted into figures and each frequency (answer given to an item) was converted into percentage scores as given below. The results included the sample of CHI individuals and their families - 18 CHI individuals and 10 family members.

2. PARTICIPANT CHARACTERISTICS

Demographic details are shown (tabulated in percentages, see table 1) below. There were 13 males and 5 females in the present study. Table 1 shows that the majority of the closed head injured males in the study were in the 35-64 age group (92.3%), while a large percentage of females were also in the 35-65 age group (60 %), in other age groups, data for females was evenly distributed, for example, in the 14-24, (20%) and 25-34 (20%) age groups.

Table 1: Demographic Details

	Head Injured		Familymember
Characteristic	**Male % (n=13)**	**Female % (n=5)**	**Female % (n=10)**
Age (Years)			
14-24	-	20.0	-
25-34	7.7	20.0	10.0
35-64	92.3	60.0	80.0
65 & over	-	-	10.0
Marital Status			
Single	15.4	60.0	
Married	61.5	-	
De facto	-	-	
Divorced	23.0	-	
boy/girl friend	-	40.0	

Table 2: Highest premorbid educational level (Head-injury group)

	Secondary	Tertiary
Male % (n=13)	61.5	38.5
Female % (n=5)	60.0	40.0

Note: The above percentages do not necessarily indicate that these many subjects actually completed secondary or tertiary education, but rather that they had reached the said level of education.

Table 3
Percentage of people grouped according to their date of accident

	%
pre 1977	5.5
1977 - 1982 (> 15 years)	11.1
1983 - 1988 (>10 years)	27.8
1989 - 1992 (2-4 years)	55.6

3. EDUCATION

As can be seen from table 2, all the CHI participants had reached either a secondary level of education (had started or completed secondary school), (61.5% of males & 60% of females), or a tertiary level of education (either started tertiary education or completed a qualification at a tertiary institute), (38.5% of males, & 40% of females).

4. TIME OF ACCIDENT AND SEVERITY OF INJURY

Over half of the participants in this study had acquired their CHI between 2-4 years ago (55.6%), while approximately 28% acquired their CHI more than 10 years ago, with a further 11% acquiring their head injury more than 15 years ago. However only 5.5% of the CHI participants acquired their head injury before 1977 (see table 3).

According to the Post-Traumatic Amnesia Scale (PTA) a high number of the CHI participants (nearly 60%) were very severely head injured (comatosed between 1-4 weeks). Approximately 20% were severely head injured (comatosed between 1-7 days) and about 10% were moderately head injured (comatosed between 1-24 hours days). A further 10% were extremely head injured (comatosed more than 4 weeks), (see figure 3).

5. RELATIONSHIP STATUS

Although relationship status (see table 4) indicated that from 38.9% of head-injured individuals that were married pre-injury, 33.3% remained married after the head-injury, most of these individuals acknowledged that the first 2 years after the

TABLE 4 CHI SUBJECTS' RELATIONSHIP STATUS PRE AND POST HEAD INJURY (n=18) %		
Relationship status	**Pre-injury**	**Post-injury**
Single	27.8	50.0
Married	38.9	33.3
De facto	11.1	-
boy/girl friend	22.2	-
Divorced	-	5.6
Separated	-	11.1

injury were the most strained or difficult as far as marriage was concerned. The CHI adults described themselves as being more demanding to live with and felt that they only retained these relationships because they had been longstanding ones. The CHI individuals that reported either divorcing their partner (5.6%) or being separated from their partners(11.1%), or not remaining in a previous relationship after the head-injury (22.2%), reported this to be the case because of the fact that they were no longer capable of making 'decisions' and described themselves as having become *'followers'* rather than joint-decision makers.

6. EMPLOYMENT

All the CHI subjects in the present study reported being in full-time employment (100%), which also included being self-employed (having own business) before the head-injury. However after the head-injury only 11.1% remained in full-time employment (see table 5). Of the individuals that did remain in full-time employment (11%), reported being in much less demanding positions now than their previous jobs before the head injury. This was also the case with individuals who were in part-time positions. Over half (55.5%) of the CHI subjects reported being on some sort of government subsidy (unemployment benefit or accident compensation) after their head-injuries, while a small proportion (16.7%) decided to further their studies at a tertiary institution. It was signified from the results therefore that over half of the CHI participants, as indicated above, were currently receiving their major income from ACC (accident compensation) or similar. There was one hundred percent agreement reached between family members and the CHI participants on details in this section.

TABLE 5 EMPLOYMENT STATUS PRE AND POST HEAD INJURY FOR CHI SUBJECTS (n=18) %		
Employment Status	**Pre-injury**	**Post-injury**
Full-time work	72.2	11.1
Own business	27.8%	-
Unemployed	-	11.1
Homemakers	-	16.7
Students	-	16.7
Beneficiaries	-	44.4

Most of the family participants reported that their injured members were still experiencing financial difficulties as a result of their head injury. They had faced a substantial drop in both income and standard of living. All the participants claimed that they found difficulty in the change of status they had experienced as a result of either a loss in their jobs, or having to go back to their previous place of employment but, to lesser positions with lesser responsibilities. The CHI participants also reported that their status within the family had changed because of the loss in income and work status, for example, they were no longer seen as making an important contribution to improving their family's standard of living.

Most of the participants in this study commented on the lack of knowledge in the community about head injury. They felt that any rehabilitation process should include educating the community and work place on the changes that had occurred to the CHI individual after the head-injury. In addition, most participants suggested that any form of vocational support would have been useful, especially vocational guidance for those that had lost their previous jobs or were no longer able to keep their jobs.

7. DETAILS OF HEAD INJURY

Most of the subjects in this study (83.3%) had suffered diffuse intracerebral damage (see table 6 & appendix 11) with secondary swelling (edema) or bleeding of the brain (haematoma and haemorrhage) or bruising (contusions). Over half the subjects acquired their head-injuries through motor vehicle accidents (55.6%), others acquired the injuries through falls (16.7%), some were hit by a vehicle or an object (22.2%), and the remaining 5.5% had a congenital defect.

TABLE 6: TYPES OF HEAD INJURY (n=18) %	
Diffuse Intracerebral damage	83.3%
Haematomas and contusions	83.3%
Others (focal damage and congenital)	16.7%

8. THE CLOSED HEAD-INJURY PHYSICAL SCALE

Ratings of perceived changes indicated that more of the CHI subjects tended to rate the changes on this scale more seriously. However negative physical impairment was acknowledged by both groups (see table 7 and figures 1). In the Auditory area (mainly sensitivity to certain noises and intolerance of background noise was reported), 61.1% of the CHI subjects compared to 10% of family members reported being markedly impaired. In the Tactile area (numbness, pins and needles, and the inability to discriminate between temperatures was reported), half of the CHI subjects reported being markedly impaired whilst only 30% of the family members reported marked impairment. In the Visuo-spatial (double-vision or a deterioration in vision was reported) and Motor Control regions (spastic paralysis, hemiparesis and ataxia), more of the CHI individuals once again rated themselves as being more impaired than the ratings provided by family members (88.9% of the CHI adults versus 70% of the family members in the visuo-spatial area, and 77.8% of the CHI adults versus 60% of the family members in the motor control region). However the CHI subjects indicated no loss for smell and taste, whereas 10% of the family members in each of these cases (smell and taste) indicated marked impairment in these areas (for example, the family having to cook more flavoursome meals in order to receive a positive response of taste and smell from the head-injured member).

Further analysis(see figure 7) more clearly illustrated how much difference there was in the perceptions (moderate to marked impairment) in the 6 areas of functioning for the two groups. For example, this figure illustrated that about 57%

TABLE 7: AREAS OF DIFFICULTY

PARTICIPANTS AND FAMILY MEMBERS RATINGS OF DEFICITS IN THE CLOSED HEAD INJURY PHYSICAL SCALE

	No loss		Mild loss		Moderate loss		Markedly impaired	
	P	**FM**	**P**	**FM**	**P**	**FM**	**P**	**FM**
Auditory	22.2	90.0	11.1	-	5.6	-	61.1	10.0
Tactile	50.0	70.0	-	-	-	-	50.0	30.0
Visuo-spatial	11.1	20.0	-	-	-	10.0	88.9	70.0
Smell	100.0	90.0	-	-	-	-	-	10.0
Taste	100.0	90.0	-	-	-	-	-	10.0
Motor control	11.1	40.0	-	-	11.1	-	77.8	60.0

Note: P = Participant, FM = Family member.

Participants and Family Members' Ratings of Deficits in the Closed Head Injury Physical Scale

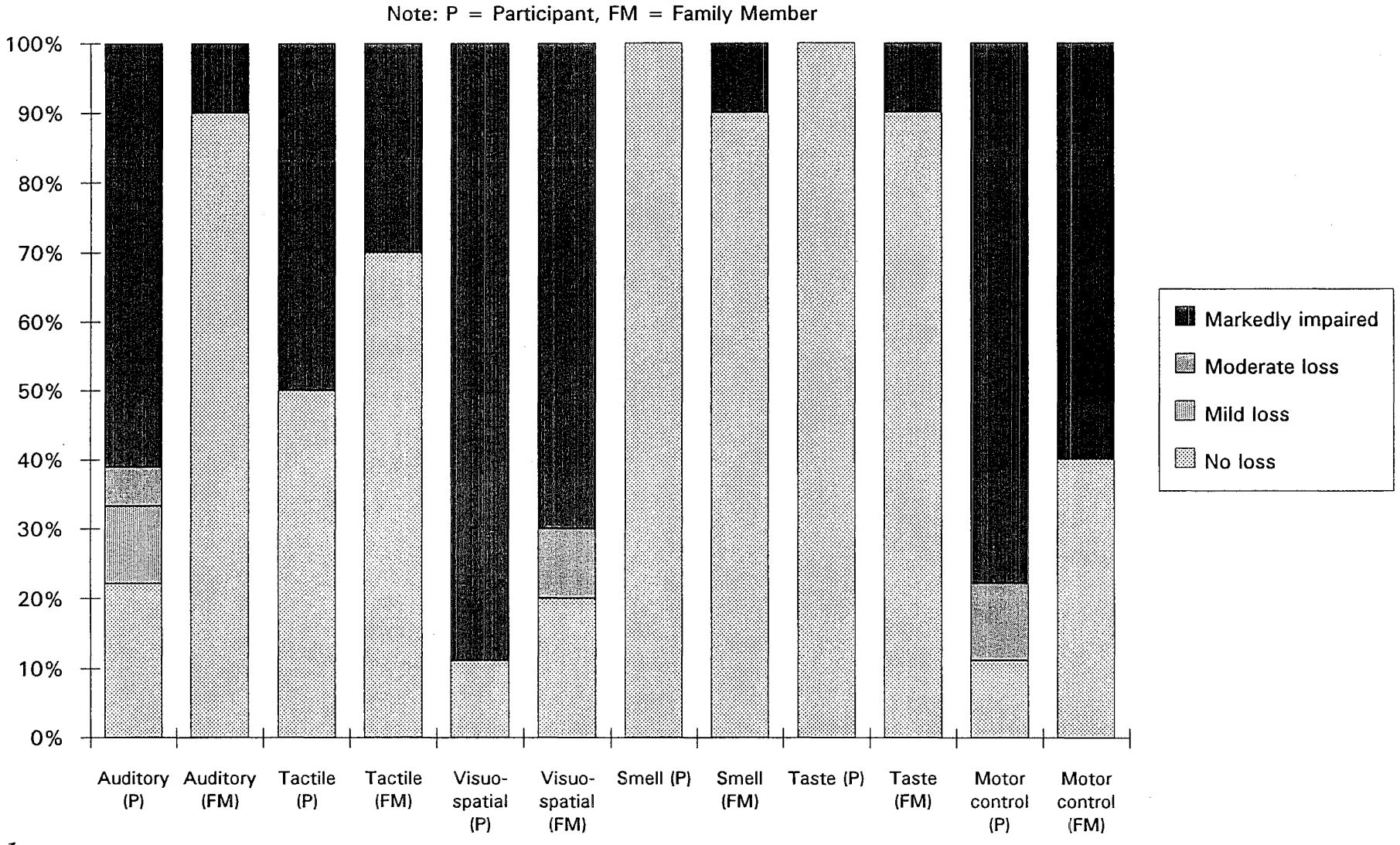


Figure 1

more, or a greater proportion of the CHI subjects than their family members perceived moderate to marked impairment in the Auditory area. The differential for the two groups in responses was not so large in the Tactile area but once again showing that 20% more of the CHI subjects found this area to be a problem for them. The differential in the Visuo-spatial area was quite small showing that only 10% more of the CHI participants found this area to be of a greater problem, indicating that generally there was agreement on the amount impairment in this area. As can be seen from figure 7, the next two categories smell and taste were more of a problem for the family members (10% more of the family members), but this difference was small, with general agreement about the lack of impairment in this area. The final area in this scale (motor control) was more of a problem for the CHI participants (28.9% more of the CHI adults found a problem in this area), than the family members.

In summary a major motor disorder, such as a spastic paralysis, hemiparesis or ataxia was reported by a large number of participants (see above). A major sensory deficit was reported by well over half of the CHI participants as indicated above, but this was reported generally as being a part of an hemisphere injury with an associated motor disturbance. Despite a moderate to marked impairment of motor disability, independence in locomotion had been achieved after 2 years of the head injury. Seventeen out of eighteen subjects were able to walk unaided, and only one was chairbound. Nearly all the subjects (89%) reported having no paramedical therapy (physiotherapy, occupational therapy, speech or cognitive therapy) at the time of testing. Only 2 CHI subjects appeared to be receiving therapy of some kind. Therefore, almost all the subjects (89%) reported self-care

activities, this information was verified by the family members. Almost all the CHI subjects (94.4%) seemed to have achieved normal speech and communication ability at the time of testing.

The additional comments that were made by the CHI subjects included, the head-injured subjects in part blaming the physical dimensions (auditory, tactile, visuo-spatial skills and motor control) as the reasons for not being able to keep their previous employment. For example, the CHI subjects felt that their auditory dysfunction (not being able to withstand background noise or any noise) stopped them from working in their previous place of work. Other comments included the problems of fatigue. This was described as a problem area which appears to have precluded the CHI subjects from returning to work or pursuing recreational or social type of activities.

Most of the participants in providing extra information in regard to rehabilitation suggestions, reported that most of the CHI participants had only received traditional hospital treatment in the physical aspects of their injuries (physiotherapy, occupational therapy, speech therapy etc.). However, even though the traditional hospital help was needed at the time of their (CHI participants) injuries, they reported that they had not received any other form of help which was much needed in terms of ongoing comprehensive care.

9. THE CLOSED HEAD-INJURY COGNITIVE SCALE

On the closed head-injury cognitive scale, generally both CHI subjects and the family members appeared to indicate an agreement, rating changes more seriously on all dimensions (see table 8, and figure 2). All family members perceived marked

TABLE 8: AREAS OF DIFFICULTY

PARTICIPANTS AND FAMILY MEMBERS RATINGS OF DEFICITS IN THE CLOSED HEAD INJURY

COGNITIVE SCALE

	No loss		Mild loss		Moderate loss		Markedly impaired	
	P	**FM**	**P**	**FM**	**P**	**FM**	**P**	**FM**
Memory	-	-	-	-	22.2	-	77.8	100.0
Learning new information	5.6	30.0	-	20.0	16.7	-	77.7	50.0
Thought processes	5.6	-	5.6	20.0	-	20.0	88.8	60.0
Concentration	16.7	-	-	20.0	27.8	30.0	55.5	50.0
Distraction	5.6	30.0	16.7	-	5.6	-	72.1	70.0
Higher cognitive functioning	22.2	10.0	5.6	-	-	-	72.2	90.0
Language	88.8	88.8	5.6	5.6	5.6	5.6	-	-

Note: P = Participants, FM = Family members.

Participants and Family Members' Ratings of Deficits in the Closed Head Injury Cognitive Scale

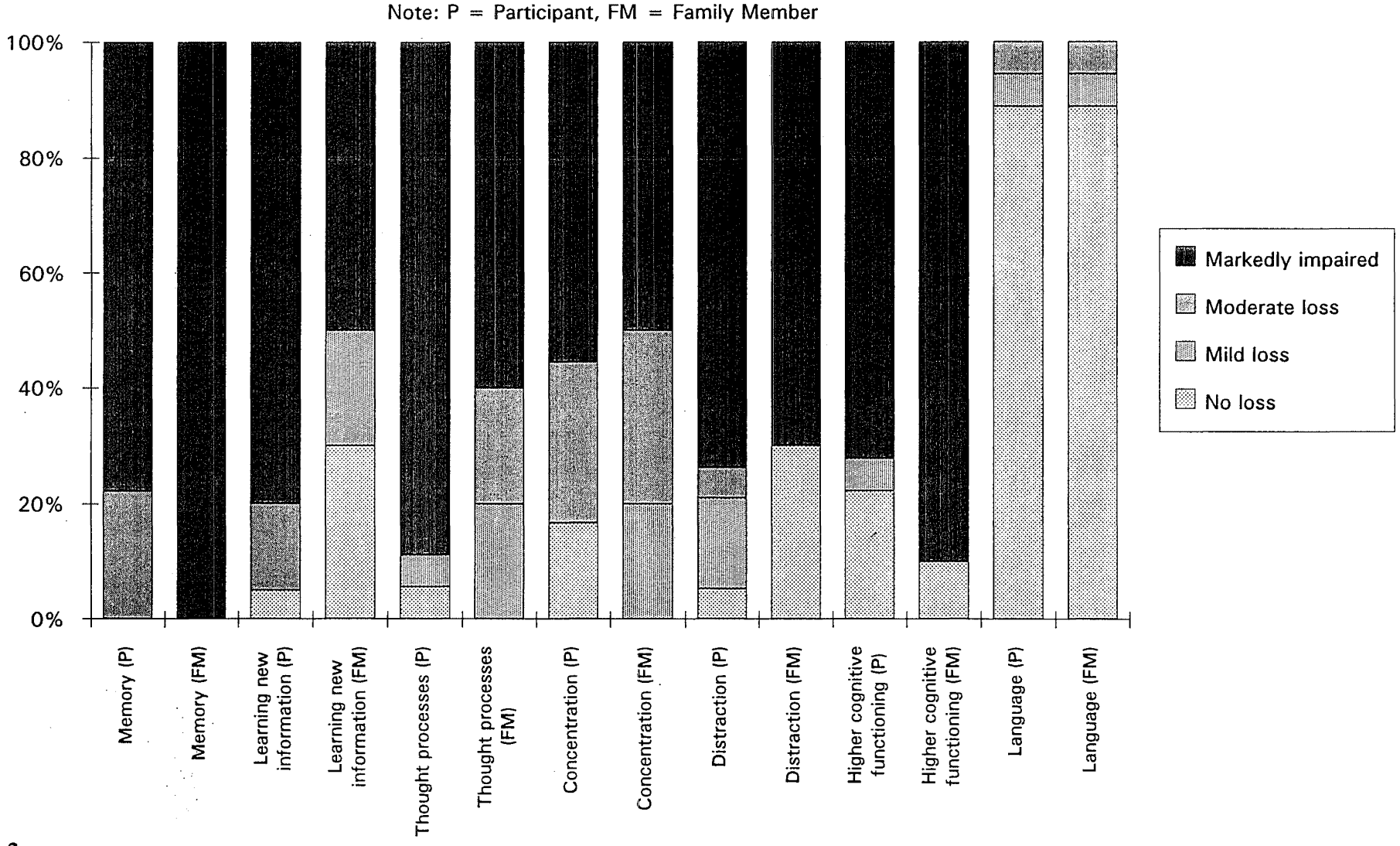


Figure 2

impairment in memory after head-injury (100%) and almost 80% of CHI subjects also perceived being markedly impaired in memory. Therefore both groups agreed a moderate to marked loss in memory (see figure 2). Short-term and recent memories were perceived as being the most impaired by both groups, while remote memory was perceived as being the least impaired, with most CHI adults easily recalling earlier experiences and childhood facts. Most CHI individuals indicated having to either carry a 'diary', or a small note book, in an attempt to remember simple tasks (picking up children from school or what supermarket they generally go to), before venturing out of the house. Most CHI subjects (88.8%) assessed changes in the 'learning new information' dimension more seriously than the family members (50%). It should be noted that an additional 14% of family members indicated some (mild) loss (see figure 2). However the majority (90%) of family members' rated 'higher cognitive functioning' as being markedly impaired, compared to the CHI subjects (72.2%). CHI subjects (88.8%) assessed their 'thought processes' as having slowed down or requiring a great deal of effort after their head-injury, while 60% of the family members' thought this was the case . There was agreement on the other remaining dimensions between the two groups, such as, 'distraction', both groups felt that this area was impaired . Only 5.6% of the CHI subjects reported no impairment in distraction but, as many as 30% of the family members' claimed there was no impairment in this region. Both groups reached an agreement as far as marked impaired concentration was concerned, 55.5% of the CHI subjects versus 50% of the family members' felt concentration was seriously affected. Furthermore up to 80% of people in both groups confirmed moderate to marked impairment in concentration. It should be noted

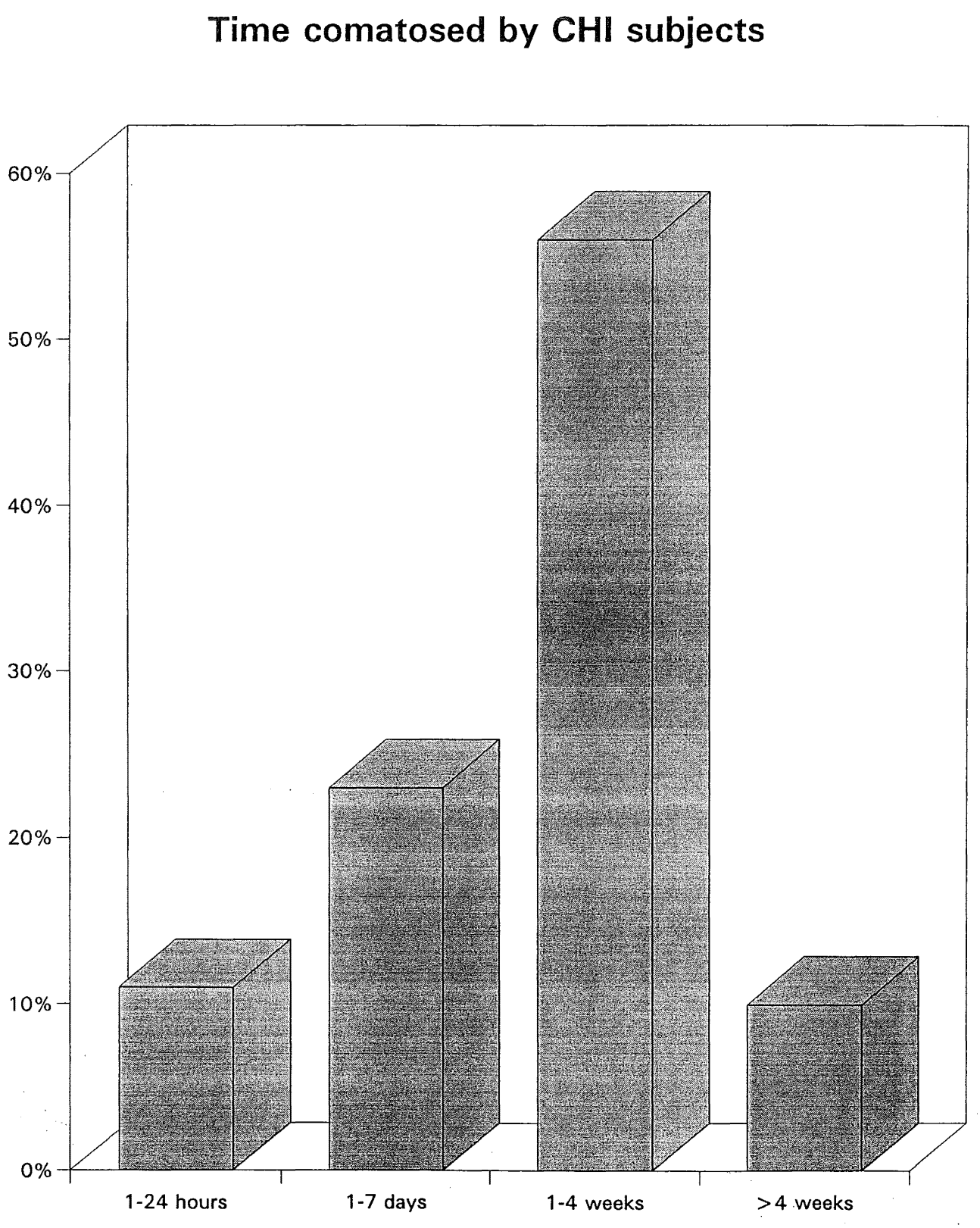

Time comatosed by CHI subjects
60%
50%
40%
30%
20%
10%
0%
1-24 hours
1-7 days
1-4 weeks
>4 weeks

Figure 3

however that 17% of CHI subjects perceived no loss in concentration (see figure 2). There was a high level of agreement (88.8%) between the two groups in the language area, that no loss had occurred concerning language.

Further analysis indicated more clearly the differences in the responses as far as moderate to marked impairment is concerned for each of the dimensions on this scale (see figure 8). For example, the differences in responses was detected in only 5 categories. The largest difference seemed to have been in the 'learning new information' dimension, where about 44% more of the CHI participants thought there was difficulty in this dimension. Generally there was an agreement reached on the 'thought processes dimension', with only about 18% more of the CHI participants finding this dimension a problem for them. There was only a 3.3% difference (more of the CHI participants) in the 'concentration dimension' between the two groups, indicating a high level of agreement in this dimension as the difference is very insignificant. The same is observed for the 'distraction' dimension, where the difference is only by 7.7% (more of CHI participants). The last dimension where a difference was detected was in the 'higher cognitive functioning. More of the family members (18%) reported a difficulty in this dimension, but once again this difference is small indicating that there was a general level of agreement reached for this dimension.

Overall, more of CHI adults regarded their cognitive abilities as having suffered more seriously since the head-injury than did the family members'. This difference however was quite small in most of the dimensions as reported above. Therefore it seems that there was a general level of agreement between the two groups with the majority of individuals (over half of the individuals) in both groups

perceiving negative changes on almost all the dimensions of the cognitive scale after head-injury.

As far as rehabilitation suggestions are concerned, most CHI participants and their families reported that the closest they came to receiving cognitive help was in the form of speech therapist only . Psychological help was indicated as being unavailable to most of the participants in this study.

10. THE STANDARDISED SCALES

10.1. The Beck Depression Inventory Scores

The Beck Depression Inventory scores were tabulated (see table 9) showing two clusters. The first cluster, which consisted of over half of CHI individuals (55.6%), reported no or minimal depression (scored less than 10 points on the Beck Depression Inventory). However a considerable number of CHI individuals (44.4%) reported being mild to moderately depressed (scored between 10-18 points on the Beck Depression Inventory) at the time of testing. Most of the participants reported having received no professional help in alleviating their depressive symptoms.

10.2. State-Trait Anxiety Inventory

The scores of the State-Trait Anxiety Inventory were tabulated and reported on table 10. The majority of CHI adults (94.4%) indicated not being anxious on the state dimension, for example, these individuals were not anxious at the time of testing. However 61.1% of the CHI adults reported *generally* feeling more

TABLE 9: BECK DEPRESSION INVENTORY SCORES AS PERCEIVED BY CHI SUBJECTS (n=18) %	
No or minimal depression	**Mild to moderate depression**
56.6	44.4

TABLE 10: ANXIETY SCORES USING THE STAI-Y1 AND STAI Y-2 SCALE AS PERCEIVED BY THE CHI SUBJECTS (n=18) %			
	Not anxious	**1SD**	**2SD**
STAI-Y1	94.4	5.6	-
STAI-Y2	27.8	61.1	11.1

Note: 1SD and 2SD refers to either one or two standard deviations (more anxious) from the standardised data.

anxious than the normative sample (1 standard deviation from the mean trait score). Only 27.8% of the CHI adults reported generally not being anxious. Once again most of the participants reported no access to professional services in regard to help with their anxiety problems.

10.3. The State Trait Anger Expression Inventory

The results of the State-Trait Anger Expression Inventory are shown on table 11. Only a small percentage (from 5.6% on some dimensions of the scale, to 27.8%) of CHI individuals (over the 75th percentile, in this case, percentile scores grouped under 80-89 and 90-99 as indicated on the table) are likely to experience or express angry feelings to a degree that may interfere with optimal functioning. This is in comparison to individuals with lower scores, that is, between the 25th and 75th percentiles. Characteristics of persons with high scores (over the 75th percentile) are given below.

Individuals with high State-Anger scores (over the 75th percentile) (44.4%) are said to be experiencing relatively intense angry feelings, however relative to the Trait-Anger dimension, these angry feelings are likely to be situationally determined. Only if scores in the Ax/in dimension are also elevated for these individuals, is it more likely to reflect chronic anger. In this case, this was true for 16.6% of the CHI adults, who are more likely to have chronic anger problems.

Only 5.6% of the CHI adults have reported high scores in the Trait-Anger dimension. This reflects the number of individuals who frequently experience angry feelings and often feel that they are treated unfairly by others. These people are also more likely to experience a great deal of frustration. How much they

TABLE 11: STATE-TRAIT ANGER EXPRESSION (STAXI) INVENTORY SCORES AS PERCEIVED BY THE CHI SUBJECTS							
n=18 %							
Percentiles	**S-Anger**	**T-Anger**	**T-Anger/R**	**Ax/in**	**Ax/out**	**Ax/con**	**Ax/ex**
0-9	-	-	11.1	-	5.6	16.7	-
10-19	-	72	-	-	33.3	-	-
20-29	-	5.6	44.4	38.9	-	5.6	5.6
30-39	-	-	-	5.6	-	38.9	-
40-49	-	5.6	-	33.3	16.7	27.8	-
50-59	-	-	-	5.6	27.8	-	5.6
60-69	55.6	5.6	38.9	-	5.6	-	33.3
70-79	-	5.6	-	-	-	11.1	38.9
80-89	16.6	-	-	-	5.6	-	5.6
90-99	27.8	5.6	5.6	16.6	5.6	-	11.1

Note: Between 20-29 to 70-79 is in the normal range, individuals above 75 are likely to experience and/or express angry feelings to a degree that may interfere with optimal functioning.

express, suppress or control their anger can be inferred from their scores on the Ax/in, Ax/out and Ax/con dimensions.

A very small number (5.6%) of CHI adults reported high scores in the Trait-Anger/T dimension. This dimension reflects persons with quick-tempers who readily express their angry feelings with little provocation. These individuals are said to be often impulsive and lacking in anger control, but they are not necessarily vicious and/or vindictive in attacking others. Persons with high Trait-Anger/T who also have a high Ax/con scores may be authoritarian and use anger for intimidation. No CHI adults reported high scores in the Ax/con dimension in this case.

The Trait anger/R dimension only affected 5.6% of the CHI subjects with high scores. These individuals are said to be highly sensitive to criticism, perceived affronts, and negative evaluation by others. They tend to experience intense feelings of anger under these circumstances.

The Ax/in dimension only affected a small number of CHI adults (16.6%). Persons with high scores on this dimension frequently experience intense angry feelings, but tend to suppress these feelings of anger, rather than expressing them either physically or verbally. Some individuals who have high Ax/in scores may also have high Ax/out scores, which simply means that these persons, in some situations, suppress anger but in other situations express their anger. This was not the case for any of the CHI subjects in this study. In fact, none of the CHI adults gained high scores for the Ax/con dimension.

High scores in the Ax/con dimension would have meant expressed aggression towards other persons or objects in the environment. Anger-out may be expressed

physically (assaulting others) slamming doors, verbally criticising others in forms of insults, threats and extreme use of profanity. This was not the case for any of the CHI subjects in the present study.

The Ax/ex dimension affected 16.7% of the CHI individuals who gained high scores on this dimension. These persons are said to experience intense angry feelings, which may be both suppressed or expressed in aggressive behaviour. Those individuals with higher Ax/in (0%) and Ax/out scores (5.6%), may manifest anger in many facets of behaviour. These persons in addition are more likely to experience difficulty in interpersonal relationships and are at a higher risk (than the general population) for the development of medical disorders (heart problems etc.).

Individuals with low scores (below the 25th percentile) on the Trait-Anger, Ax/in and Ax/out dimensions are reported to experience, express or suppress relatively little anger. However these persons may excessively use defenses of denial and repression to protect themselves from experiencing unacceptable angry feelings. In this case, denial and repression may be used as a primary means for coping with and avoiding anger.

Most family members believed that the anger problems that were expressed by their injured member were a reflection of a change in personality that had occurred after the head injury. However the family members felt that they (both families and CHI adults) did not have any access to services offering emotional help for this problem.

11. THE HEAD INJURY BEHAVIOUR SCALE

Ratings of perceived change for the behaviour scale was tabulated (see appendix 13), and these were graphically illustrated. (see figures 4-6). Overall it appears that more family members' rated various dimensions of behaviours as being problematic, compared to the ratings perceived by the CHI subjects.

In item 1 (Anger, difficulty controlling temper), 70% of family members felt that this dimension was problematic for them compared to 38.9% CHI subjects. In item 2 (Impatience, upset when needs not met), 80% of family members found this behaviour to be problematic, while 50% of CHI subjects found this to be so. However in item 3 (frequent complaining), the reverse was true, more CHI subjects found this behaviour was problematic (33.3%) than the family members' (10%). Item 4 (Aggressive, violent behaviour) an agreement was reached between the two groups on this item with approximately 20% finding this behaviour a problem. However on Item 5 (impulsivity; does things without thinking), 70% of the family members' found this item to be a problem for them compared to only 11.1% of the CHI subjects. Item 6 (argumentative: often disputes topics) an agreement was reached between the two groups of approximately 40% across the two groups finding this item a problem. Item 7 (Lack control over behaviour) more of the family members' found this behaviour to be problematic (30%) compared to only 11.1% of the CHI finding this item to be a problem. Item 8 (overly dependent; rely on others unnecessarily; does not do things for self), most subjects in both groups did not find this behaviour problematic for them (80% of family members' versus 66.7% of CHI subjects). Item 9 (Poor decision making), more family members thought this item to be problematic (50%) compared to CHI

subjects (27.8%). Item 10, (Childish; at times behaviour immature), half of the family members' thought this behaviour was a problem for them, while only 11.1% of the CHI subjects thought this was the case for them. Item 11, (Poor insight), once again, over half of the family members (60%) felt this was a problem for them, while only 27.8% of the CHI adults felt this was so for them. Item 12. (Difficulty in becoming interested in things), 80% of family members' did not think this was problematic, and 61.1% of the CHI subjects felt this was also not a problem for them. Item 13, (Lack of initiative), both groups agreed on this dimension, with the majority in both groups not seeing it as a problem behaviour. Item 14 (Irritable; snappy; grumpy), and Item 15 (Sudden/rapid mood change), dimensions were agreed upon by both groups, with at least half of the subjects from each group finding item 14 a problem, and on 30% from each groups finding item 15 a problem. Item 16, (Anxious, tense; uptight), this item was had agreement between two groups with 50% from each group finding this behaviour to be a problem. Item 17, (Depressed; low mood), more of the family members (48%) found this to be a problem compared to only 33.3% of the CHI subjects. Item 18, (Irresponsible; can't always be trusted), the majority from each group did not report this behaviour to be a problem for them. Items 19, (Overly sensitive; easily upset) and 20 (Lack motivation) was a problem for more of the CHI group than family members'.

In summary, from the above analysis of each item, it appears evident that at least half of the above behaviours were perceived as being more problematic for family members than for the CHI adults, while some items showed agreement between the two groups (see figure 6). The items that were more problematic for

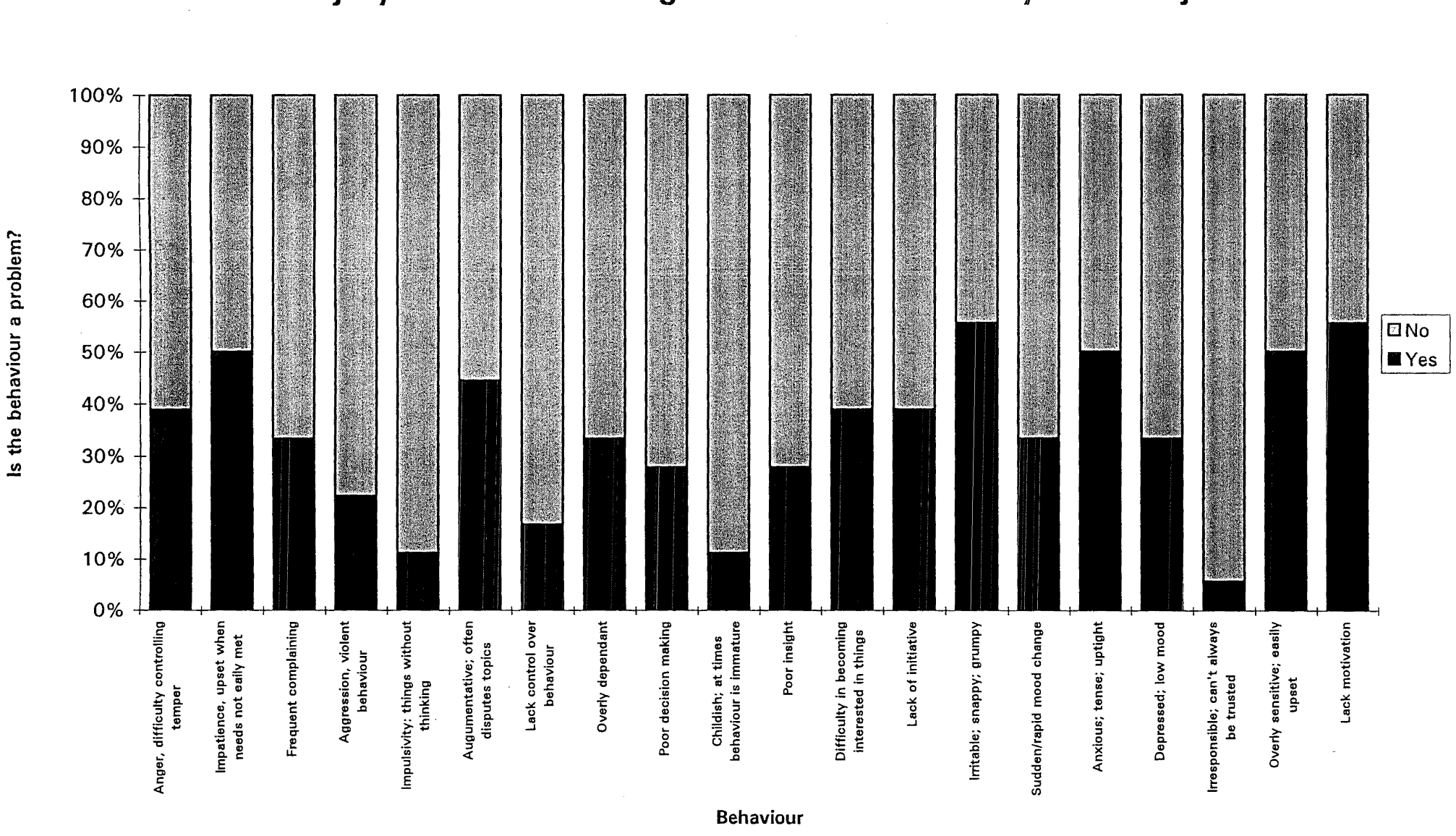

Head Injury Behaviour Rating Scale as Perceived by CHI Subjects
Is the behaviour a problem?
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
No
Yes
Anger, difficulty controlling temper
Impatience, upset when needs not eaily met
Frequent complaining
Aggression, violent behaviour
Impulsivity; things without thinking
Augumentative; often disputes topics
Lack control over behaviour
Overly dependant
Poor decision making
Childish; at times behaviour is immature
Poor insight
Difficulty in becoming interested in things
Lack of initiative
Irritable; snappy; grumpy
Sudden/rapid mood change
Anxious; tense; uptight
Depressed; low mood
Irresponsible; can't always be trusted
Overly sensitive; easily upset
Lack motivation
Behaviour

Figure 4

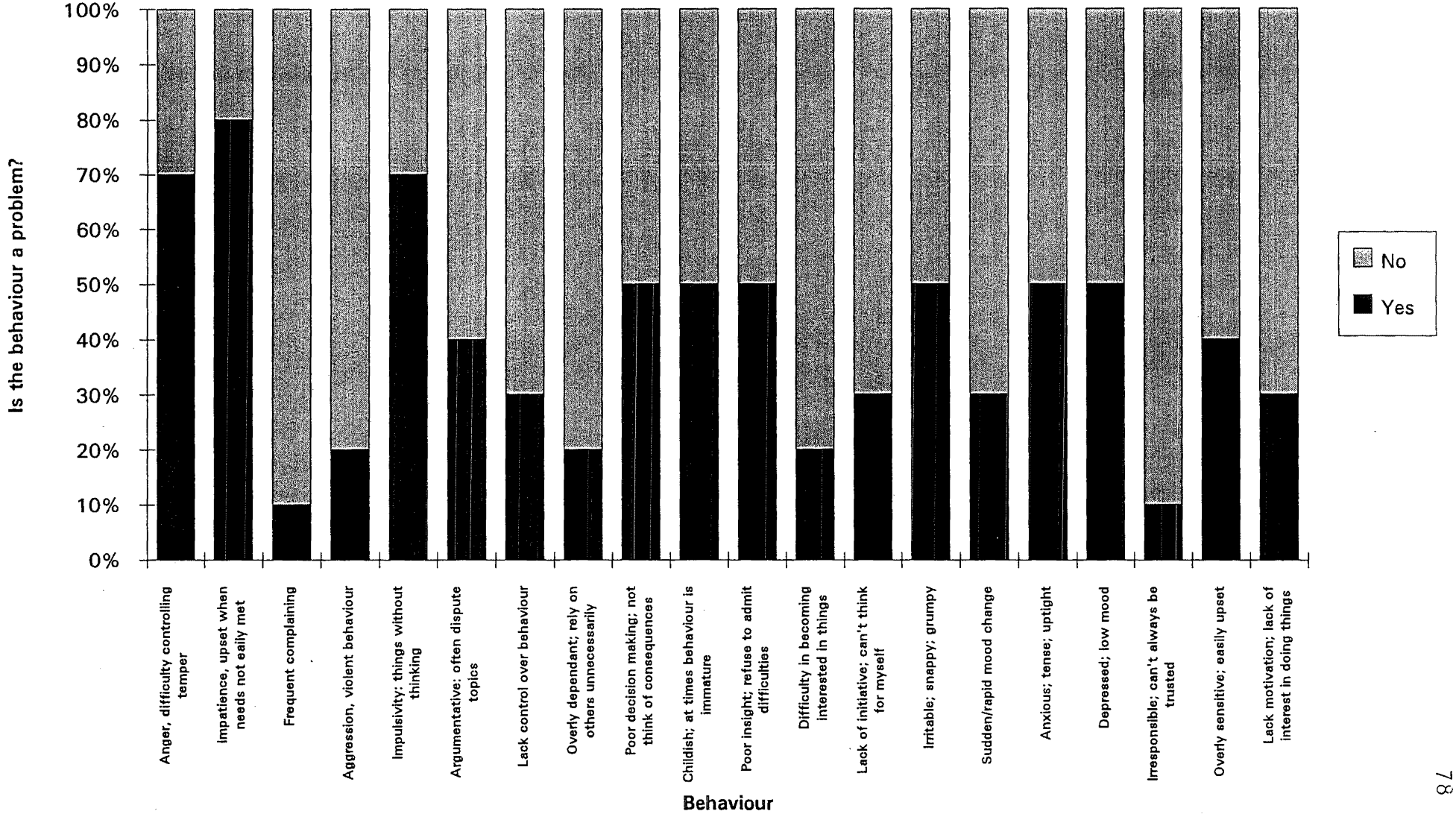
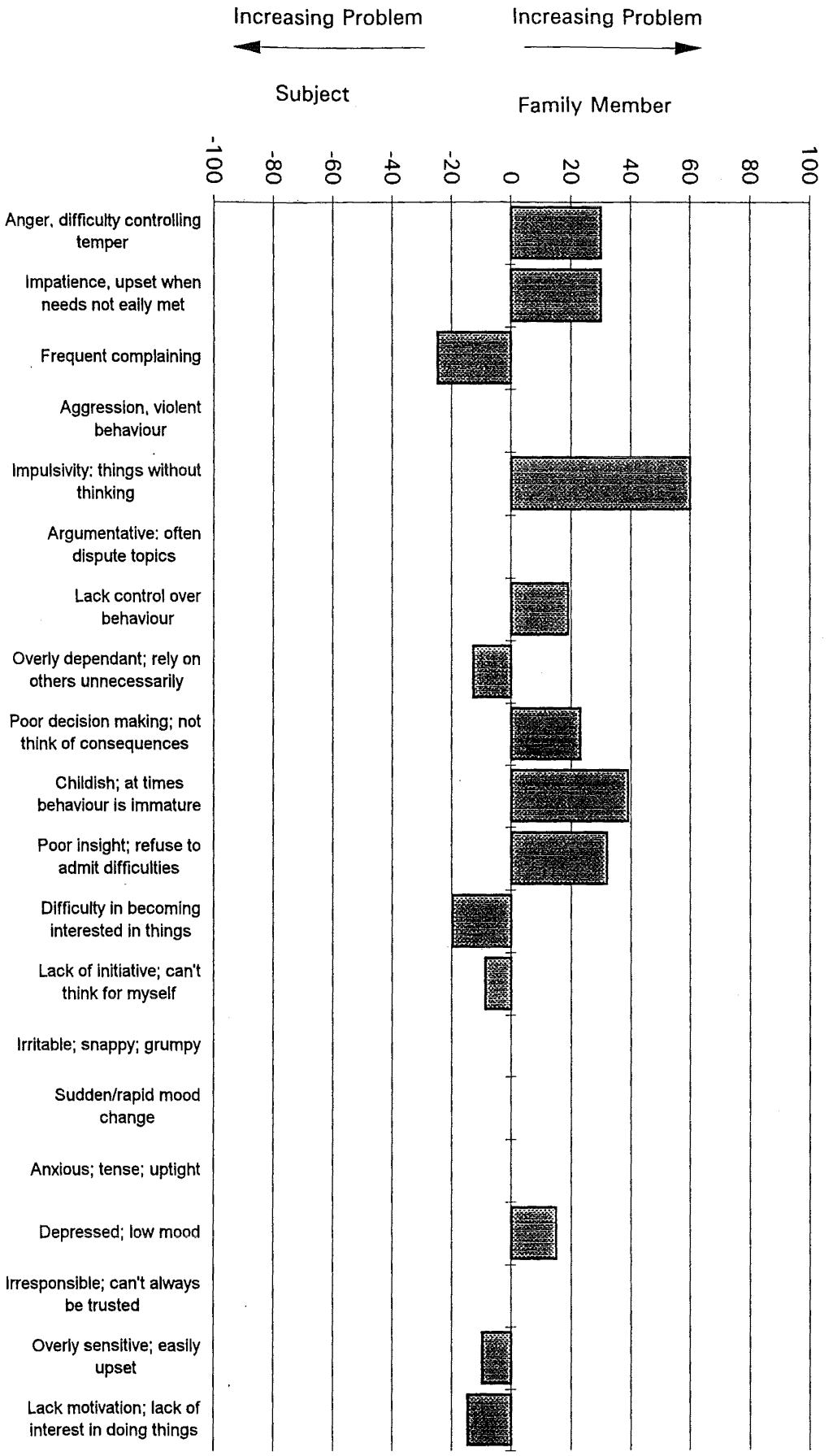

Head Injury Behaviour Rating Scale as Perceived by Family Members
Is the behaviour a problem?
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
No
Yes
Anger, difficulty controlling temper
Impatience, upset when needs not eaily met
Frequent complaining
Aggression, violent behaviour
Impulsivity; things without thinking
Argumentative; often dispute topics
Lack control over behaviour
Overly dependant; rely on others unnecessarily
Poor decision making; not think of consequences
Childish; at times behaviour is immature
Poor insight; refuse to admit difficulties
Difficulty in becoming interested in things
Lack of initiative; can't think for myself
Irritable; snappy; grumpy
Sudden/rapid mood change
Anxious; tense; uptight
Depressed; low mood
Irresponsible; can't always be trusted
Overly sensitive; easily upset
Lack motivation; lack of interest in doing things
Behaviour

Figure 5

Figure 6



Differential in Identification that Behaviour Problems are Evident as Perceived by Family Members and CHI subjects


Differential in Identification that Physical Problems Moderate to Marked are Evident as Perceived by Family Members and CHI subjects
Increasing Problem
Family Member
Increasing Problem
Subject
100
80
60
40
20
0
-20
-40
-60
-80
-100
Auditory
Tactile
Visuo-spatial
Smell
Taste
Motor control

Figure 7

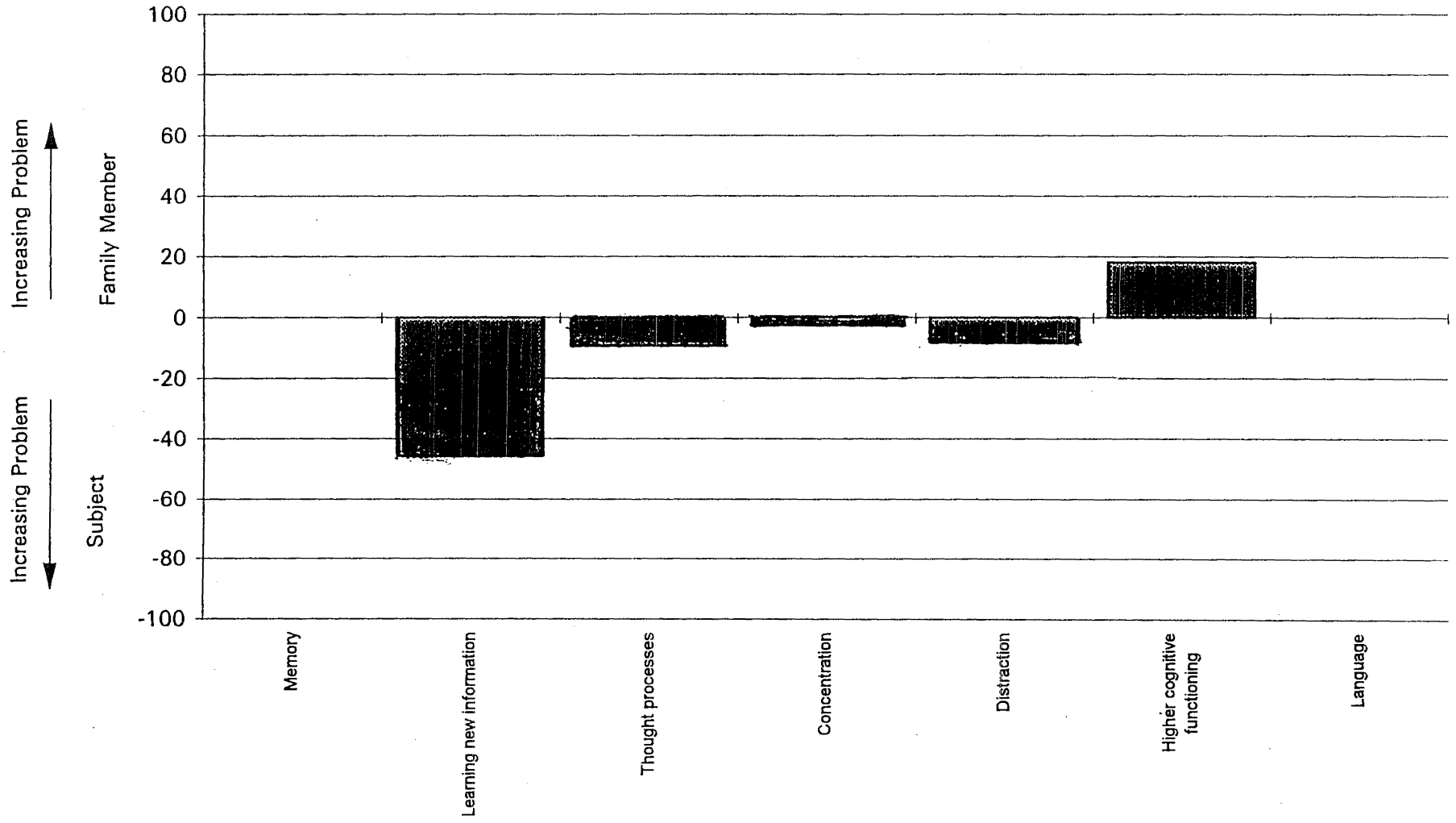

Differential in Identification that Cognitive Problems Moderate to Marked are Evident as Perceived by Family Members and CHI subjects
Increasing Problem
Family Member
Increasing Problem
Subject
100
80
60
40
20
0
-20
-40
-60
-80
-100
Memory
Learning new information
Thought processes
Concentration
Distraction
Higher cognitive functioning
Language

Figure 8

the CHI group were items 3, 8, 12, 13, 19, 20. Item 3 (frequent complaining), item 8 (overly dependent), item 12 (difficulty becoming interested in things), item 13 (lack of initiative), item 19 (overly sensitive, easily upset), item 20 (lack of motivation). However there was less than a 10% differential in the perceived difficulty in items 13 and 19. Items that were more problematic for family members were items 1, 2, 5, 7, 9, 10, 11, 17. These items are item 1 (anger), item 2, (impatience), item 5, (impulsivity), item 7, (lack of control over behaviour), item 9, (poor decision making), item 10, (childishness), item 11, (poor insight), and item 17, (depressed, low mood). An agreement was reached on items 4, 6, 14, 15, 16, and 18. These items are item 4, (aggression), item 6, (argumentative), item 14, (irritable), item 15, (sudden/rapid mood change), item 16, (anxious), and item 16, (irresponsible) (see figure 6).

The families of the CHI participants reiterated the lack of professional help in dealing with the behavioural sequelae to head injury. They felt that this area was of most concern to them and the most difficult to deal with. For example, they felt it was difficult coping on a daily basis with the labile nature of some of the behaviours exhibited by their CHI members.

CHAPTER 4

DISCUSSION

The main purpose of this study was to examine perceptual differences in CHI adults and family members. One main relationship was hypothesised, that changes after head injury would be perceived differentially by the head-injured subjects and the families studied. Specifically, that the head injured subjects would differ in their perceptions, but only in the cognitive and behavioural sequelae to head injury. For example, that more of the family members will tend to rate changes particularly in the behavioural area (negatively) than the closed head-injured person. But cognitive changes will be rated (negatively) by more of the head-injured subjects than the family members. Furthermore, that the CHI subjects were likely to report depression, anxiety and anger problems two years or more after their head injury. However, physical changes after head-injury were expected to be perceived similarly (negatively) by family members and the head-injured adults. In addition, both groups will similarly perceive negative changes in employment status of the head-injured adult after CHI.

In the first section of this chapter the findings from this study and their implications will be discussed. The second section addresses the limitations in the design of this study, and in the final section, directions for further research are considered.

1. GENERAL DISCUSSION

In the present study males were represented at a rate just over two times (2.3:1) higher than females. This is similar to other studies of this kind, that males generally have a 2.2. times higher rate than females in the head-injury population. However, only 7.7% of the males fell into the 14-24 age group, while 40% of the females in this study fell in that age group, which is not in accordance with overseas research that usually half of the head-injury population (predominantly male) fall into the 14-25 age group. Most of the family members who responded and participated in this study were females, with the majority being either wives or mothers of the person with a head-injury and almost all (90%) being in the 35-65 age group

In support of the main hypothesis, CHI adults and family members did report significant physical, cognitive, behavioural and negative emotional changes after head-injury. The first subhypothesis was also supported that a greater proportion of the family members tended to rate negative changes in the behavioural areas than the CHI persons, however agreement in some items was also reached between the two groups in this area. The second subhypthesis was not supported that more of the CHI subjects perceived difficulty in physical changes, than did the family members. The third subhypothesis that cognitive changes will be rated negatively by more of the head-injured subjects than the family members was also not supported. Generally both groups indicated an agreement that serious cognitive changes had occurred on all dimensions of the cognitive scale after the head-injury. However the two groups were able to be differentiated on the basis of their

perceptions of the seriousness of the cognitive changes in some dimensions. The fourth subhypothesis was supported that CHI subjects indicated depression, anxiety and anger-control problems. The last subhypothesis was supported that negative changes in employment would be perceived by all the subjects in the present study.

Findings from the present survey suggested that CHI adults with moderate to extremely severe head injury (according to the Post-Traumatic Amnesia Scale), are a heterogeneous population. In the present study, the multiple and varied intracranial pathologies that occurred were reflected. Although the severity of injury may increase difficulties according to past research, the present study indicated that individual limitations varied according to many factors, such as the nature of the injury, pre-injury functioning and post-injury adjustment. However all the subjects (head-injured and family members) reported specifically impairments in all four areas of functioning investigated, namely, cognitive processing, behavioural and emotional changes, and physical impairments. All the problems encountered in the above areas of functioning appear to have affected other crucial areas, such as, family and social readjustments, which seem to have necessitated extensive and continued relearning for the CHI adults. As was expected substantial vocational changes were also described by most of CHI subjects involved in this study. For all the CHI subjects, family involvement was an integral part of the recovery process, which is consistent with past research (Bergland & Thomas, 1991; Brooks et al., 1986; Brooks, 1991; Caine, 1989; Car, 1993; Dufour et al., 1992; Florian et al., 1991; Kreutzer et al., 1988; Lezak,

1978, 1986 & 1988; Jones & Lorman, 1988; Rape et al., 1992; Smith, 1993; Sumners, 1994; Quine et al., 1988).

1.1. Physical Outcome

The second subhypothesis which is in regard to physical outcome of head injury was not supported in that more of the CHI subjects perceived difficulty in physical changes than did the family members. Comparison of the categories made in the CHI physical scale (sensory deficits and motor functioning) between the head-injured adults and the family members indicated that more of the CHI group perceived negative changes after the head injury, however negative physical impairment was acknowledged by both groups. Whilst the family members perceived marked impairment in two more categories of the physical scale (smell and taste), the CHI adults reported more serious impairment in all the other categories (auditory, tactile, visual and motor) of the CHI physical scale. Nevertheless, this finding is consistent with previous research indicating that changes in the physical sequelae of CHI is more likely to be acknowledged by both the CHI adult and the family, but seldom seems to result in significant handicap (Ben-Yishay et al., 1985; Brooks, et al., 1981, 1986; Chisholm, 1987; Fearnside et al., 1993; Gloag, 1985; Hendryx, 1989; Humphrey, 1978; Lezak, 1983, 1986, 1988; McClelland, 1986; McGuire & Greenwood, 1990; McKinlay et al., 1981; Smith, 1993).

Although major disturbances such as a spastic paralysis, hemiparesis or ataxia were present in a great deal of the CHI subjects, independence was obtained in locomotion in 89% of all the CHI subjects. This appeared to be a reflection not

only in the early involvement of paramedical therapists, but in most cases the patient's determination. Sensory disturbance, when present, seemed to be generally a part of a hemisphere injury. It did not appear to influence significantly, the ability to mobilise the head-injured subject.

It became increasingly apparent throughout this survey that the long-term cognitive, behavioural and emotional sequelae to closed head injury exceeded the physical sequelae as far as the CHI adult and the family members were concerned. This finding is clearly consistent with past research (Chisholm, 1987, Gloag, 1985, Lezak, 1986, Hendryx, 1989, Humphrey, 1978, McGuire & Greewood, 1990, McKinlay et al., 1981). Nevertheless it was indicated by all the subjects in this study, that the neurophysical injury experienced by the CHI subjects should not be minimised or that the neuropsychological and the physical outcomes of closed head-injury should not be considered in isolation, as all these people (especially family members) appeared distressed and frustrated by the additional burden created by these physical types of injuries. For example, the CHI subjects were not able to resume work, or recreational or social participation because of the inability to tolerate any type of noise and would fatigue easily as a result of the head-injury.

The problems of fatigue were voiced by both groups as continually affecting progress in all areas of functioning. This is in agreement with past research (Car, 1993; Fenelick & Ryan, 1991, Lezak, 1983) that the loss of stamina and endurance are common problems because of the lack of energy affecting the individual's performance in all areas of daily life.

1.2. Cognitive outcome

The third subhypothesis, that cognitive changes will be rated negatively by more of the head-injured participants than the family members was not supported. Cognitive impairment, in line with past research, was acknowledged by both groups (CHI adults and the families) as being one of the most troublesome regarding readjustment after head-injury (Brooks, 1990; Fenelick & Ryan; 1991; Lezak, 1983). Overall, cognitive impairment was perceived similarly by family members and CHI participants. For example, the head-injured participants and family members generally agreed on the magnitude of cognitive changes that had been experienced by the head-injured subjects. However both groups identified different areas that were of most concern to them. The most significant difference seemed to have been in the 'learning new information' dimension, (elaborated below) where about 44% more of the CHI subjects than the family members indicated a difficulty on this dimension.

All family members (100%) perceived marked memory impairment moreso than the CHI adults (77.8%). Nevertheless both groups agreed on a moderate to marked loss in memory. However from these, there was 100% agreement between these two groups on short-term memory being affected the most, more than the remote memory. All subjects (both CHI adults and family members) in this study held memory problems responsible in causing major disruptions in their lives. All other areas of functioning (in the cognitive area), were said to be affected because of the deficits in memory. All the CHI subjects reported having to write most things down as reminders of tasks they want to carry out on a daily basis, from

grocery items, names of people they will be likely to see that day, reminder to check the mailbox, to pegging their washing on the line.

More family participants than their head-injured members(90% versus 72.2%) perceived changes in higher cognitive functioning. For example decreased planning and organisational abilities, and a general slower response rate (slowness to process information), impairing their ability to initiate and monitor their activities, was said to (by family members) contribute to a great deal of difficulties regarding progress. Decision making by the CHI group was indicated also as being a problem area for both groups. Most CHI participants admitted leaving most of the decisions about everyday events and major events to close others, and described themselves as being 'followers' rather than leaders or joint decision-makers. These findings in agreement are common amongst the head-injured according to past literature (Lezak, 1983; Richardson, 1990; Smith, 1993, Struss & Benson, 1984), that the CHI individuals may lack the 'building block' cognitive skills needed to perform executive functioning, and cannot understand the abstract. They often have difficulties learning from their mistakes or successes.

More CHI subjects than the family members(88% versus 50%) found learning new information difficult and tended to rely on their past knowledge rather than tackle any new task or learn new information. However an additional 14% of family members indicated some mild loss. This finding is in accordance with past literature that most patients with severe or very severe injuries experience difficulty learning new information (Admovich, 1991, Brooks, 1984; Lezak, 1986; Smith, 1993; Webster & Scott, 1983). Difficulties of learning new information consisted of slowed learning ability which may be compounded by the

inability to retrieve new information, even though they may have stored new information (Adamovich, 1991).

Both groups agreed that distraction was another major obstacle that affected other areas of cognitive functioning. For example, not being able to socialise or hold a conversation or read a book, when there was anything else going on in the background, such as, music being played, other people talking, television being on, the telephone ringing and so forth. It is well documented that this very intolerance of socialising in general, can lead to family isolation (Lezak, 1988).

Once again, there was agreement reached between the two groups as far as deficits in concentration were concerned with approximately 80% of the subjects in both groups confirming moderate to marked impairment. It should be noted however that 17% of the CHI subjects perceived no loss. In agreement with Adamovich (1991) and Lezak (1983) most of the subjects in this study reported impaired attention and concentration in three ways, firstly, the inability to initiate and sustain attention, secondly, the inability to shift the focus of attention when appropriate and thirdly, the inhibition of the inappropriate shifting of the focus of attention.

The majority of subjects in both groups (88.8%) reported normal speech and communication ability. Levin et al. (1982) stated that aphasia after closed head-injury seems to be rare. However 'subclinical' or 'minimal' aphasia is common sequel of closed head injury (Levin et al., 1982). Most CHI subjects claimed they were able to communicate adequately after 6 months of the head-injury, however there were a large number of individual differences reported.

1.3. Emotional Outcome (standardised scales)

The fourth subhypothesis was supported in that a large number of CHI subjects indicated mild to moderate depression at the time of testing (44.4%), and a large number indicated suffering from general anxiety (61%) at the time of testing. In addition up to 28% of CHI subjects indicated anger-control problems, in that their anger would be likely to interfere with their optimal functioning. The use of standardised clinical scales in this section indicated specifically the following. The BDI (Beck Depression Inventory) showed that just under half (44.4%) of the CHI individuals were suffering from mild to moderate clinical depression at the time of testing. Which is in accordance with 55.6% (over half) of the CHI individuals reported either no or minimal depression. Of the subjects that reported no or minimal depression, all of these subjects admitted having had a period of low mood or depression at some stage during the recovery phase. In addition, approximately half of the CHI subjects also reported having suicidal thoughts at some stage during the recovery phase, two subjects went as far as to make suicide plans, but all the CHI subjects were assessed to be at a low suicide risk at the time of testing. This finding of the existence of depression, as reported by all the CHI individuals, is consistent with past literature that depression is one of the most common finding in the emotional sequelae to head-injury (Gloag, 1985; Lezak, 1983, 1987; Jones & Lorman, 1988; McClelland, 1988, McKinlay et al., 1981; Smith, 1993).

All the subjects had some commonalities in their answers to the reasons for low mood or depression. These consisted of lowered confidence, generally in all matters, because of the various deficits that have occurred as a result of the head-

injury. Memory problems, fatigue and motivational difficulties, pressure at work, for those that worked, and pressure to find work for those that did not work, and physical problems were the most frequently reported reasons for the onset of depression. One subject reported leaving town because he could not stand the lower status he had acquired after the head-injury, as he could no longer keep his pre-injury job. In line with, and in support of past research (Bond, 1984; Fordyce et al. 1983; Godfrey et al., 1993; Prigatano, 1986), most of the CHI subjects (88.8%) reported the onset of depression to coincide with their emotional reaction to the awareness of the disability they were faced with. The higher functioning subjects in this study, pre-injury, appeared to have more insight into their deficits (verified by their families) than did the other subjects. Furthermore, these subjects (higher functioning) seemed to be coping better with this realisation (of deficits) at the time of testing. In addition all the subjects in the present study, reported having had experienced the feeling, or had clinged to the hope that they may return to their former status at some stage in the past. However this did not appear to be the case at the time of testing as most subjects seemed to have accepted the changes they had suffered as a result of the head injury.

The majority of the CHI adults (94.4%) reported no anxiety at the time of testing (STAI-Y1 dimension), however a considerable amount of CHI adults (61.1%) reported generally feeling more anxious than the standardised sample (STAI-Y2 dimension). For example, these individuals scored at least 1 deviation from the mean score of the standardisation sample. Only 27.8% of the CHI adults reported generally not being anxious. This finding of general anxiety (being anxious generally in everyday life) among the CHI group, is in support with a

considerable amount of past literature (Fordyce et al., 1983; Gloag, 1985; Lezak, 1983, 1987, 1988; Jones & Lorman, 1988; McClelland, 1988; Orsillo & McCaffrey, 1992; Smith, 1993). According to Orsillo & McCaffrey (1992). Anxiety post CHI can be experienced due to the increased awareness of the neuropsychological impairment and the physical impairment of the head-injury. According to one study (Fordyce et al., 1983), the manifestation of anxiety and depression was obvious in patients 6 months post-injury than the patients less than 6 months post-injury. Perhaps this explains the high number of individuals (61.1%) with anxiety problems in the present study. The nature of this type of research (lack of a longitudinal focus) of the present study only allows speculation in this area.

The STAXI (State-Trait Anger Expression Inventory) was used in an attempt to ascertain the number of adults who perceived anger control problems. Overall, this scale indicated that there were only a small number of individuals (up to 28%) with anger problems that were above the clinical cut-off, in other words, those individuals who are likely to express angry feelings to a degree that may interfere with optimal functioning (scores above the 75th percentile). For example, results indicated that 45% of the individuals (this category contained the highest number of individuals compared to other categories or dimensions of the STAXI), had high S-Anger scores. Elevated scores in S-Anger represented chronic anger, such as, experiencing relatively intense angry feelings in certain situations only. Only 6% of individuals scored highly on the T-Anger dimension, which reflects the number of individuals who frequently experience angry feelings when they feel that they are being treated unfairly by others. On the T-Anger/R dimension, once again only

6% of the individuals received high scores. This dimension represents those individuals who are quick-tempered and who readily express their angry feelings with little provocation. The Ax/in dimension also only affected a small number of individuals (16%) which highlighted those persons who frequently experience intense angry feelings, but tended to suppress these feelings of anger, rather than expressing them physically or verbally. Only 6% of individuals (Ax/out dimension) expressed their anger. None of the individuals in this study felt that they expressed their aggression or anger onto other people or objects in the environment (low scores in the Ax/con dimension). While a small percentage (11%) of CHI individuals scored highly on the Ax/ex dimension. This reflected those people who are likely to express intense angry feelings, which may both be suppressed or expressed in aggressive behaviour.

Individuals with low scores (below the 25th percentile) reported experiencing, expressing or suppressing relatively little anger (T-Anger - 72%, Ax/out 38.9%). In all other categories, (apart from the T-Anger and Ax/out dimensions) CHI adults scored between the 25th and 75th percentiles, which is indicated by the STAXI to be in the normal range. Therefore from the above interpretation of the STAXI scale of the head-injured persons that did perceive anger problems, the majority of these people (44.4%) perceived only situational anger. Of the subjects that perceived situational anger, most reported this to be the direct effects of the head-injury. This finding may reflect a change in personality in these individuals, which is well documented in research (Levin et al., 1982, Smith, 1993; McKinlay et al., 1981). For example, family members stated that anger was a part of other behavioural and personality changes that had occurred in the head-injured

individual. The family members believed that the anger was either a result of the direct consequences of brain dysfunction (head injury itself) or secondarily through psychological reaction to the head injury (increased insight). In this study a high number of family members (85%) reported that personality changes had occurred. The more frequently cited personality changes reported seemed to be anger, lower frustration tolerance and irritability. The present study appears to be the first study to have used the STAXI, therefore comparisons of the results obtained from this scale cannot be made with other studies. This scale could have some potential for use, especially for future research looking at anger problems in the head-injured population. Most of the CHI subjects identified both anger and aggression problems earlier on in the sequelae of their head-injury, but felt that this and other behavioural problems were more under control (expressed more appropriately) now (at least post 2 years of head-injury).

Although some of the CHI adults reported having been assessed at some stage during their recovery phase, the assessments were made in order to justify the CHI individuals receiving a government subsidy (for example, an A.C.C. grant). Moreover, the assessment usually included neurophysical and cognitive deficits but rarely involved assessment of emotional deficits. Furthermore, no help, in form of counselling or therapy was every offered by any organisation, especially therapy that included family members. Most of the people in this study indicated the need to access services with the cognitive and psychosocial (emotional and behavioural) sequelae of head-injury over the more traditional focus on the neurophysical aspects of the injury. This is in support with a recent survey (Car, 1993) where the same was indicated. None of the CHI group surveyed in this study indicated

having received professional treatment (apart from medical and physical treatments). All the people (both groups) in the present study felt that the more comprehensive professional service, incorporating the psychosocial aspects, would have been the most helpful.

1.4. Behavioural outcome

The first subhypothesis was supported that a greater proportion of the family members tended to rate negative changes in the behavioural areas than the CHI subjects, however agreement was also reached in some items. The behavioural outcome was determined in the present study using two versions of the 'Head-injury Behaviour Rating Scale'. Overall it was indicated that a greater proportion of the family members rated various dimensions of behaviours as being problematic compared to the ratings of the head-injured subjects. The following items were considered to be problematic for more of the family members, but not so problematic for the head-injured subjects. These are in areas of (some behavioural excesses) anger, difficulty controlling temper, impatience, impulsivity, lack of control over behaviour, poor decision making, childishness, poor insight, depression and low mood. Agreement was reached on a further 6 items listed which are aggression, argumentative, irritable, sudden/rapid mood changes, anxiety and irresponsibility. But the CHI group only reported these items which are problematic for them than the family members, frequent complaining, overly dependent, difficulty becoming interested in things, and lack of motivation, suggesting that perhaps the CHI adults are more concerned with behavioural

deficits or tend to recognise that there is a difficulty in these areas (of behavioural deficits) than problems in behavioural excesses.

The above result, that the behaviours of the head-injured adults are more of a concern to family members supports past literature (Brooks et al., 1986; Chisholm, 1987; Gloag, 1985; Hendryx, 1989; Lezak, 1986, 1987; McGuire & Greenwood, 1990; McKinlay et al. 1981). However the CHI adults appeared equally as distressed about some of the behaviours. This finding also supports current literature that the consequences of behavioural problems may have profound and lasting effect upon both the individual and close others (Eames & Wood, 1985; Gloag, 1985, Lezak, 1986; Smith, 1993). An interesting pattern that seems to have emerged from the results in this section is that the family members tended to report more frequent problems that were similar in nature, for example, behaviour excesses (irritability, impulsivity and demanding behaviours), while the head-injured group seemed to be reporting more problems in the behaviour deficits (lack of motivation and withdrawal.). Most of the subjects in both groups reported that the problems were of more concern to them earlier on in the recovery phase (a year following the head-injury) than now (at the time of testing), as the CHI group appear to be more in control of the behaviours. The family members voiced their concerns at the lack of help for both groups in the emotional sequelae to head-injury, in comparison with the physical sequelae. Once again, both groups felt that physical and medical help was more forthcoming or available, but emotional help was almost non-existent.

1.5 Vocational outcome

Substantial changes in employment were reported after closed head-injury. While all the CHI subjects (100%) reported being in full-time employment (including having their own business) before their head-injury, only 11% remained in full-time employment after their head injury. Of the individuals that did return to their previous place of work, all reported being in less demanding positions, as a result of not being able to intellectually function in the same way as they did pre-injury. The individuals that returned to the workplace, but in a part-time capacity also reported having had to return to less demanding positions. A large number of the CHI subjects (55%) in the present study reported currently receiving government support. It is signified from the results that a large proportion of head injured people were currently still receiving their major income from ACC or other government income support. According to family members, a significant number of the CHI subjects were still experiencing financial difficulties as a result of their head-injury. Of the people currently in employment (full or part-time),all reported substantial drop in income and standard of living. In some instances families had been reduced from a double to a single income. In another case, a family member reported a complete role reversal in their household especially where young children were involved. For example, the head-injured person had to look after the children while a family member (partner) was forced to work full-time. In this case the family member reported living in fear, especially earlier on (not long after the CHI), while at work, in case of housefire and other dangerous issues, as the head-injured member was very forgetful (leaving food cooking on the stove and becoming distracted with other activities).

Some studies (Oddy et al., 1978, Rappaport et al., 1989) indicated that the majority of patients with CHI did return to work, but that this depended largely on the severity of injury. Perhaps this is why the majority of the CHI subjects in the present study did not return to work, as a result of the prolonger periods of PTA or unconsciousness (the majority of subjects were very severely injured). This finding is in support of the literature on vocational outcomes, that of the CHI adults that do return to work have to accept jobs with less responsibility (McClelland, 1986; Rappaport et al., 1989). McClelland (1986) stated that age is often the deciding factor as to who can successfully return to work. For example, the younger the person is, most commonly the more successful. In the present study, most of the subjects were in the 35 to 65 age group (92.3% males, 60% females), this may have accounted for the high number of individuals in this study that were unable to return to full-time employment. However in agreement with Bullard and Cutshaw (1991), predicting vocational outcome for this population can prove to be difficult because of the complexity, diffuseness and uniqueness of each injury.

Most people that returned to work in some capacity commented on the lack of knowledge in the community on head-injury. Because of the invisibility of the injury, they felt that their employers and colleagues did not understand the change in the head-injured person, especially because they physically looked the same as they did pre-injury. They felt that education and information regarding head-injury in the community should be given by rehabilitation or vocational people working in this area as employers required a better knowledge and understanding of the head-injury. Most head-injured subjects and family members felt that vocational

guidance (vocational based community rehabilitation service) after the head-injury, especially for those that are no longer able to sustain their previous positions, would have been helpful in the readjustment process.

As was the case in Car's (1993) survey, most individuals in this study felt that realistic goals should be set by the interventions offered, in regards the individual's capability of carrying out particular vocational tasks. Also in agreement with Car (1993), most people (both groups) reported a serious lack of facilities and services for the head-injured adult at all levels including the lack of vocational help.

1.6 Rehabilitation suggestions

Rehabilitation suggestions were made by all the participants in this study and may prove useful in devising a rehabilitation model for closed head-injured adults. Generally most of the participants, especially family members voiced their concerns at the lack of and limited availability of rehabilitation services with skilled professionals in head-injury rehabilitation. Most participants reported the lack of a co-ordinated approach to rehabilitation. The family members felt it would have been very useful to have been seen by a professional or equivalent at the time of the head-injury. This person than could have channelled the family of the head-injured patient into various areas. For example, information given to the family regarding the details of the head-injury, given the opportunity to attend educational classes on head-injury and the likely changes expected to occur, management advice to family members regarding how to cope with the patient once at home, financial advice regarding government subsidy, such as how to go about applying for ACC (government subsidy) etc. and how much subsidy the CHI is likely to

receive and so forth. Most participants in the present study reported feeling being "*frustrated and fed-up*" with the lack of advice, especially on ACC matters subsequently after the head-injury.

Most CHI participants reported having only received traditional hospital treatment and only in the physical aspects of their injury (physiotherapist, occupational therapist and speech therapist) and only for a limited time after their head injury. However no help was offered by the psychosocial services (family support, advocacy, counselling, clinical psychologist and social work). One CHI participant reported having received no help whatsoever, because he did not acquire any physical handicaps (he suffered congenital head-injury) he received only traditional medical treatment at the time of his injury and was discharged. The family member in this case reported being very distressed at the lack of help or information at that time, and indicated needing access to services with the cognitive and psychosocial sequelae of head-injury, which seems to have been a lower priority to the more traditional focus.

In summary, a well co-ordinated *package* of care with a comprehensive interdisciplinary rehabilitation approach, as opposed to the traditional medical approach, was described as being in much demand for the CHI individuals and their families. The following quote was typical of the comments that were received during this survey regarding rehabilitation. *"It is time that the medical professionals had a more co-ordinated approach to rehabilitation of people with complex disabilities and that there is a need for a rehabilitation hospital for brain injured people to go to straight from general hospital where they can be fully assessed and rehabilitated physically and hopefully mentally as well with regular*

follow-ups over the first two years" (family member of a closed head-injured adult).

2. LIMITATIONS OF THE PRESENT RESEARCH

The limitations of the present study must be considered in conjunction with its findings. This study was designed as exploratory, therefore the sample size was small and not randomly selected, and the data are largely descriptive (qualitative instead of quantitative). The main limitation of this study is the small sample size (n = 18). There were two reasons for the use of a small sample size, the first one being that the present study had restricted its focus to one area (Canterbury) instead of on a more national basis. Secondly, the data was collected through the Head Injury Society and through advertisement placed in the media. Perhaps this only captured those individuals who were either more motivated to respond, or were in a better position to respond (having family care to motivate them and offer transportation etc.). Furthermore, perhaps this study only captured those who had worked through their psychosocial sequelae (grief issues) to head-injury, and those that were either still in denial of the head-injury or were still grieving did not respond. The selection of participants, "participant bias" (Dane, 1990) could have created a "volunteer error". For example, those who refused to participate in this study may have represented a selection factor which is highly significant. As mentioned above, participants that did not respond and were unwilling to participate in the research, may have suffered from either denial or grief issues. The use of a small sample means that the generalisability of the findings is difficult.

Further study in this area and comparisons with other study groups is needed to ratify these exploratory findings.

Another limitation of this study was the uneven proportion of females and males in the both groups. For instance, 13 males versus only 5 females participated as subjects who had received a head-injury. Research in this area has shown head-injury to effect the male population predominantly, this could be why the gender imbalance has occurred. Nevertheless all the family members in this study were female, causing a further gender bias. Car (1993) in her survey also found that more female family members tended to respond. Perhaps females may be more comfortable talking about personal matters, such as the psychosocial factors, than are males. Whatever the reason for the imbalance, the females perspective on head-injury (both as a head-injured subject and a family member) may be very different from male experiences. Thus the findings of this study may need to be considered with this limitation in mind.

The retrospective nature of this study should be considered when reviewing its findings. For example, CHI subjects included in this research had suffered a head-injury 2 or more years ago. Memory decay (for both groups) and the sensitivity of the topic may cause possible distortions in the data, particularly when the events, perceptions, and feelings occurred over a number of years.

As is the case of most research on head-injury, the sample is homogeneous in terms of ethnic group and the severity of head-injury. The majority of the participants in the study were Pakeha or of a European descent, and the majority of head-injured participants had a severe to very severe head injury and have lived in New Zealand for some time. In addition, most of the CHI subjects in this study

had supportive family members. These similarities create problems in generalising the findings to individuals of other head-injured groups or ethnicity.

Another, main limitation of this study concerns the procedures used to identify the consequences of CHI amongst CHI adults and that of family members. As a result of most researchers using their own structured or semi-structured interviews or questionnaires which are designed to look at specific problems associated with the head-injury, there is a serious lack of reliable and validated instruments. The experimenter in this instance had to devise instruments (Biographical data, information on the head injury, Closed head-injury Physical and Cognitive Scales), which only looked at one or two aspects of the problems the head-injured person may have experienced in the sequelae of each of those areas. This may have caused "experimenter bias" (Dane, 1990), for example, the items included in the devised instruments may have resulted in the subject's answers being limited or manipulated to indicate certain deficits only. Because the literature on both head-injury and family functioning are rather diffuse, the construction of the above scales was important to keep this specific study focused. However these instruments have breached all the common psychometric problems of reliability, validity and generalisability. Nevertheless some validity and reliability issues were ensured through the use of the clinical instruments used in this study.

Another limitation in this study concerns the lack of statistical analysis (non-parametric) which seem to have been employed in similar studies. But the results that could have been shown (significance or non-significant) by the employment of these analyses would have forced a judgment to be made on who's view of outcome is correct. Even though past literature has indicated that patients may not

be aware of their deficits, often denied or dismissed their deficits, and that family members often differ in their reporting of deficits, the purpose of this study was not to show a statistical difference or to take one view over another, but merely to document consumer opinion and consumer suggestions for the implications that can be considered for rehabilitation purposes, from the both views gained (head-injured and family members). This appeared to be adequately achieved by tabulation of the results as given above.

The final methodological limitation concerns the lack of a non-injured control group in this study. This limitation may mean that the deficits in the four areas of functioning that are described cannot be 100% guaranteed to be specific to the effects of a closed head-injury.

3. DIRECTIONS FOR FUTURE RESEARCH

Because this area of research is relatively new and fast growing, directions for future research are many and diverse. There needs to be more of a longitudinal focus on the research in this area, which follows changes in perceptions as far as psychosocial deficits are concerned. Typical qualitative studies seem to have relied on retrospective, cross-sectional methodology, which are subject to memory decay, cohort differences, and a lack of baseline data.

A lack of measuring instruments in the area of head-injury has hindered the comparability of findings across studies. More reliable and valid instruments need to be constructed and used to determine the perceptual differences between the head-injured population and that of family members.

Future research needs to focus on the experience of fathers and husbands in the area of families of the head-injured adults. Male family members, seem to be somewhat unrepresented in the family literature. Cross-cultural studies, including New Zealand studies are needed to explore differences in responses to head-injury amongst the head-injured and their families. Most literature available in this area seems to be done in the United States.

It would be fruitful for future New Zealand research to implement theoretical ideal models of care (suitable for New Zealand society), that can incorporate both the views of the head-injured adult and family members, and that of professionals working in this area. In order for this to occur, longitudinal research on the needs of the consumer and how best the professional/s can accommodate these needs at various stages may be useful.

4. SUMMARY AND CONCLUSIONS

The main relationship hypothesised in the present study was supported by making direct comparisons of perceived changes between families and closed head-injured adults on a number of dimensions. This relationship indicated that differences in perception between the closed head-injured adults and the family members occurred in the physical, cognitive and behavioural sequelae to head - injury. Furthermore that the CHI participants suffered emotional difficulties as sequelae to closed head-injury. Substantial vocational changes were also evident from making comparisons of pre and post injury vocational situation. It seems that all the above areas of functioning, namely cognitive, behavioural, physical and

emotional were disrupted after the closed head-injury as indicated by all the participants in this study. The only debate therefore appeared to have been in what items of each of the above areas were affected the most for the head-injured individual. For example, to what degree had the changes occurred following the closed head-injury. The perceptual differences indicated by the two groups in this study may have occurred due to the acquired level of understanding and awareness of the changes due to head injury, by each of the groups in the sequelae to closed head-injury. Therefore in agreement with literature in this area, the need for involving both the head-injured and the family members in the rehabilitation process remains paramount (Lezak, 1986, 1988; Smith, 1993).

The serious lack of rehabilitation facilities in the Canterbury area was highlighted in this research with most of the participants wanting a more co-ordinated approach to treatment, with an interdisciplinary focus. Perhaps the time has come for all the professionals currently working in this area to pull their resources together (as well as lobbying for more government assistance) to help care for these individuals with a ***silent*** injury .

We can all work together whether we are theorists, researchers, writers, teachers or clinicians and whether we are in New Zealand or overseas, we must work towards the same final goal of improving the quality of life for those who have the misfortune to suffer such an injury, and that of their care givers, who ultimately share their burden. We must make connections as professionals so that we can work together in a multidisciplinary way, and we must also make connections between the homes of the closed head injured individuals and

rehabilitation centres, so that these individuals can live out their daily lives with some hope, understanding, comfort and above all, some dignity.

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APPENDICES

Appendix 1

CONSENT FORM

PERCEPTIONS OF PSYCHOSOCIAL DEFICITS POST TWO YEARS AS EXPERIENCED BY CLOSED HEAD INJURED ADULTS AND THEIR FAMILIES.

I have read and understood the description of the above-named project. On this basis I agree to participate as a subject in the project, and I consent to publication of the results of the project. I understand also that I may at any time and for any reason withdraw from the project.

Signed ..... **Dated** .....

Appendix 2

University of Canterbury

Department of Psychology

INFORMATION

PERCEPTIONS OF PSYCHOSOCIAL DEFICITS POST TWO YEARS AS EXPERIENCED BY CLOSED HEAD INJURED PERSONS AND THEIR FAMILIES.

You are invited to participate as a subject in the abovenamed project.

The aim of this project is to make direct comparisons of perceived changes between families and closed head injured adults in four areas of functioning: emotional, behavioural, physical and cognitive (thinking). In New Zealand (especially in the Canterbury area) there is limited research on the perceptions (opinions)of the needs of the closed head injured persons and their families, therefore this document may prove useful in making recommendations for intervention, post two years of injury.

Your involvement in this project, as a head-injured person or as a relative, will require you to answer some questions (conducted in a semi-structured interview style) and may require you to fill out some questionnaires by circling the correct response from a choice of answers.

The cognitive (thinking) area will ask you to answer some questions verbally and will cover memory, thought processing, concentration, distraction, and higher cognitive process (planning and organising). Behavioural items in this area will cover a range of behaviours that you may have experienced and you will be

required to indicate on a questionnaire how distressing you felt the problem was for you. The physical area will require you to answer some questions verbally regarding your senses such as hearing, touch, vision, smell and motor functioning. In the assessment of the emotional area, you will be requested to complete three self report measures (short and straight forward) by indicating the best response (by circling the correct item).

The performance of the tasks may provoke mild anxiety for some subjects as it may prompt you to recall various aspects over the time of the head injury, but as this is a one-to-one testing situation, all efforts will made to ensure the comfort of all the participants.

The results of the project may be published. You can be assured of the complete confidentiality of data gathered in this investigation. To ensure anonymity and confidentiality your names will not be recorded on any of the documents involved in this project. All information gained in the course of the project remains confidential.

The project is being carried out under the direction of Dr. Stephen Hudson, who can be contacted at the University of Canterbury, Psychology Department, (Telephone: 366-7001). He will be pleased to discuss any concerns you may have about participating in the project.

The project has been reviewed and approved by the University of Canterbury Human Ethics Committee.

Nishi Parkhill

Appendix 3

PART A: CLOSED HEAD INJURY: BIOGRAPHICAL DETAILS

1. **DATE OF BIRTH**: _____/_____/_____ **SEX** M___F___
   Day Month Year

2. **EDUCATION**: (Tick highest level)
   (1) Primary School ____
   (2) Secondary School ____
   (3) Tertiary ____

3. DID YOU RECEIVE SPECIAL EDUCATION (EXTRA TUITION), OR REPEAT CLASSES, OR HAVE READING AND WRITING PROBLEMS?

   _____

   _____

   _____

4. **EMPLOYMENT:** (Tick)
   Were you employed before your head injury? Y____
   N____

   What job did you do? _____

   Are you presently employed? Y____
   N____

   If YES type of work (Tick one)

   (1) Same as preinjury ____
   (2) Sheltered ____
   (3) Unemployed ____
   (4) homemaker ____
   (5) Other (please comment)_____

   _____

5. IS YOUR WORK TODAY (Tick one)
   (1) more demanding ____
   (2) less demanding ____

Comments: _____

6. ARE YOU EMPLOYED PART OR FULL TIME :(Tick)

(1) full ____
(2) part ____
(3) unemployed ____

Comments: _____

_____

7. **RELATIONSHIP STATUS**:

What was your relationship status before head injury (Tick one)

(1) Single ____
(2) Married ____
(3) De Facto ____
(4) boy/girl friend ____
(5) Separated ____
(6) Divorced ____

8. Has this relationship changed after your head injury: (Tick one)

Y____
N____

Comments: _____

_____

_____

Appendix 4

PART B: CLOSED HEAD INJURY: DETAILS OF YOUR HEAD INJURY

1. DATE OF HEAD INJURY: _____/_____/_____
   Day Month Year

2. HOW LONG WERE YOU UNCONSCIOUS FOR AFTER YOUR HEAD INJURY? Hours/days _____

3. HOW MANY DAYS WERE YOU IN HOSPITAL? _____

   _____

4. DID YOU REQUIRE BRAIN SURGERY? Y____
   N____
   unknown ____

   Comments: _____

   _____

5. HOW DID YOU ACQUIRE YOUR HEAD INJURY?

   _____

   _____

   _____

6. DO YOU KNOW WHAT TYPE OF HEAD INJURY YOU HAVE?

   _____

   _____

7. DO YOU FEEL YOU RECEIVED ADEQUATE HELP OVER THIS TIME? DO YOU HAVE ANY SUGGESTIONS ABOUT WHAT SORT OF ADVICE OR HELP WOULD HAVE BEEN USEFUL AT THE TIME.

_____

_____

Appendix 5

CLOSED HEAD INJURY PHYSICAL SCALE

To be completed by CHI persons and a relative or friend (separately)

AUDITORY FUNCTIONING

1. In your opinion have you experienced any hearing loss since your head injury?

_____

_____

2. Are you disturbed by high pitch sounds and ringing in the head?

_____

_____

TACTILE FUNCTIONING

3. What complaints do you have regarding the loss of sensation? e.g. numbness, pins and needles; sense of touch not as discriminating; less sensitive to pain or change in temperature.

_____

_____

_____

VISUO-SPATIAL FUNCTIONING

4. What type of visual problems do you feel you have experienced? e.g. double-vision.

_____

_____

5. Have you experienced difficulties in spatial orientation? e.g. do you get lost easily when by yourself (out shopping).

_____

_____

6. Have you experienced any difficulties in distortions of body image? e.g. change in size of your hands.

_____

_____

_____

7. Do you recall experiencing visual hallucinations or illusions(distortions in what you see)? e.g.distortion of shape and sudden distance of furniture.

_____

_____

_____

SENSE OF SMELL AND TASTE

8. What have you noticed about the your sense of smell? e.g. has your sense of smell become mildly, moderately or markedly worse or do you feel it has improved or is there no change. Is your sense of taste the same as it was before your head injury?

_____

_____

_____

MOTOR FUNCTIONING

9. What evidence do you have of paralysis, muscle weakness or lack of coordination? e.g. do you have difficulty in driving, fatigue easily, suffer from loss of bowel or bladder control, or right-left disorientation.

_____

10. What are the difficulties you experience in regard to gait or posture? e.g. stiffness, restricted range of movement

11. In your opinion do you have any evidence of physically slowing down (taking a long time to do something) or physically speeding up (hyperactivity) since your head injury?

Any other comments about any of the above items

Appendix 6

CLOSED HEAD INJURY COGNITIVE SCALE

To be completed by CHI persons and relative or friend (separately)

Memory

1. HAVE YOU NOTICED A GENERAL DETERIORATION IN YOUR MEMORY? e.g. able to recognise faces but cannot remember the names.

_____

_____

Short term memory

2. CAN YOU RECALL HAVING DIFFICULTY IN REMEMBERING EVERYDAY EVENTS? e.g. able to retain a new telephone number while phoning or remembering the name of someone you just met.

_____

_____

Recent memory

3. CAN YOU REMEMBER DAY TO DAY EVENTS? e.g. what you did the day before or what you had for dinner last night or what you had for breakfast this morning.

_____

_____

Learning new information

4. DO YOU HAVE PROBLEMS LEARNING NEW INFORMATION? e.g. following instructions on how to repair something or following a recipe from a cookery book, reading a book.

_____

_____

_____

Remote memory

5. CAN YOU REMEMBER HISTORICAL FACTS (how far back can you remember) e.g. recollecting childhood events like when you got your first bike, address of your childhood home, what schools you attended etc.

_____

_____

Thought Processing

6. DO YOU FIND YOUR THINKING HAS BEEN SLOWED DOWN? e.g. taking a long time to make up your mind.

_____

_____

Poor concentration

7. IN YOUR OPINION, ARE YOU ABLE TO CONCENTRATE ADEQUATELY ON A TASK? e.g. can you sit down and read a book or the newspaper for a period of time, or can you watch right through a half an hour television programme or follow a movie and keep up with the story.

_____

_____

Distraction

8. DO YOU FEEL YOU ARE ABLE TO EASILY BECOME DISTRACTED FROM WHATEVER IT IS YOU ARE DOING? e.g. not being able to follow a conversation when there is radio or television noise in the background etc.

_____

_____

Higher cognitive processes

9. DO YOU THINK THERE IS ANY DETERIORATION IN YOUR GENERAL INTELLECTUAL FUNCTIONING? e.g. do you feel there has been a decline in your writing, spelling and calculating abilities.

_____

_____

_____

10. IS IT MORE DIFFICULT TO COPE AT WORK? e.g. is there deterioration in your thinking, drawing or constructional abilities.

_____

_____

_____

11. DO YOU HAVE PROBLEMS PLANNING AND ORGANISING ANY EVENTS MORE SO THAN YOU USE TO BEFORE YOUR INJURY? e.g. going on holiday, social events - having a dinner party, getting children ready for school.

_____

_____

12. HAVE YOU NOTICED DIFFICULTIES IN PROBLEM SOLVING? e.g. what to do when the toaster isn't working or you have a leaky roof, the car doesn't start. Has anything gone wrong around the house in the last month?

_____

_____

_____

Loss of initiation

13. DO YOU HAVE PROBLEMS INITIATING AN ACTIVITY TO IN YOUR FREE TIME? e.g. are you able to function just as well in an unstructured situation or do you need a routine and prefer to go along with somebody else.

_____

_____

Language ability

14. HAVE YOU PROBLEMS IN COMPREHENDING SPEECH? e.g. following someone's verbal instructions on how to get somewhere (responding to directions).

_____

_____

Verbal fluency

15. HAVE YOU NOTICED THAT YOU HAVE TROUBLE THINKING OF THE RIGHT WORD TO USE WHEN HAVING A CONVERSATION WITH SOMEONE?

_____

_____

16. DO YOU FEEL YOU HAVE TROUBLE SPEAKING CLEARLY? e.g. do you slur your speech at times.

_____

_____

_____

Extra Comments:

_____

_____

_____

Appendix 7

HEAD INJURY BEHAVIOUR SCALE

Individual's Version

To be completed by the individual with the head injury

Hamish P D Godfrey DipCIPs PhD
Clinical Psychology Research and Training Centre
University of Otago, New Zealand.

HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for me but causes me NO distress.
2. The behaviour is a problem for me and causes me MILD distress.
3. The behaviour is a problem for me and causes me MODERATE distress.
4. The behaviour is a problem for me and causes me SEVERE distress.

BEHAVIOUR	Is the behaviour a PROBLEM?	How much DISTRESS does problem cause?
1. Anger; difficulty controlling temper.	Y : N	1 2 3 4
2. Impatience, upset when needs not easily met.	Y : N	1 2 3 4
3. Frequent complaining.	Y : N	1 2 3 4
4. Aggression; violent behaviour.	Y : N	1 2 3 4
5. Impulsivity; things without thinking.	Y : N	1 2 3 4
6. Argumentative; often dispute topics.	Y : N	1 2 3 4
7. Lack control over behaviour; behaviour is inappropriate for social situations.	Y : N	1 2 3 4
8. Overly dependent; rely on others unnecessarily; does not do things for myself.	Y : N	1 2 3 4
9. Poor decision making; not think of consequences.	Y : N	1 2 3 4
10. Childish; at times behaviour is immature.	Y : N	1 2 3 4
11. Poor insight; refuse to admit difficulties.	Y : N	1 2 3 4
12. Difficulty in becoming interested in things.	Y : N	1 2 3 4
13. Lack of initiative; not think for myself.	Y : N	1 2 3 4

HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for me but causes me NO distress.
2. The behaviour is a problem for me and causes me MILD distress.
3. The behaviour is a problem for me and causes me MODERATE distress.
4. The behaviour is a problem for me and causes me SEVERE distress.

	BEHAVIOUR	Is the behaviour a PROBLEM?	How much DISTRESS does problem cause?
14.	Irritable; snappy; grumpy.	Y : N	1 2 3 4
15.	Sudden/rapid mood change.	Y : N	1 2 3 4
16.	Anxious; tense; uptight.	Y : N	1 2 3 4
17.	Depressed; low mood.	Y : N	1 2 3 4
18.	Irresponsible; can't always be trusted.	Y : N	1 2 3 4
19.	Overly sensitive; easily upset.	Y : N	1 2 3 4
20.	Lack motivation; lack of interest in doing things.	Y : N	1 2 3 4

HEAD INJURY BEHAVIOUR SCALE

Relative/Friend Version
To be completed by relative or friend of the individual with the head injury

Hamish P D Godfrey PhD
Clinical Psychology Research and Training Centre
University of Otago, New Zealand

Please complete 1-5 below.

1. WHAT IS YOUR DATE OF BIRTH? _____/ _____/ _____
   DAY MONTH YEAR

2. SEX: M F (circle one)

3. WHAT IS YOUR OCCUPATION? _____

4. WHAT IS YOUR RELATIONSHIP TO THE INDIVIDUAL WITH THE HEAD INJURY (circle one):
   Mother Father Spouse/Partner Sibling
   Other (please specify relationship) _____

5. DATE COMPLETED (Todays date) _____/ _____/ _____
   DAY MONTH YEAR

INSTRUCTIONS: On the next page is a list of problem behaviours the may be experiencing. Please indicate which of the behaviours listed is a problem for the sufferer by circling YES or NO as appropriate. For each problem behaviour circled YES, please indicate how much distress the behaviour causes YOU by circling a number on the scale (1-4). Remember we are asking you to report about the head injured individual's behaviour. Use the rating scale given at the top of the next page.

HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for the individual but causes me NO distress.
2. The behaviour is a problem for the individual and causes me MILD distress.
3. The behaviour is a problem for the individual and causes me MODERATE distress.
4. The behaviour is a problem for the individual and causes me SEVERE distress.

BEHAVIOUR	Is the behaviour a PROBLEM?	How much DISTRESS does problem cause?
1. Anger; difficulty controlling temper.	Y : N	1 2 3 4
2. Impatience, upset when needs not easily met.	Y : N	1 2 3 4
3. Frequent complaining.	Y : N	1 2 3 4
4. Aggression; violent behaviour.	Y : N	1 2 3 4
5. Impulsivity; things without thinking.	Y : N	1 2 3 4
6. Argumentative; often dispute topics.	Y : N	1 2 3 4
7. Lack control over behaviour; behaviour is inappropriate for social situations.	Y : N	1 2 3 4
8. Overly dependent; rely on others unnecessarily; does not do things for myself.	Y : N	1 2 3 4
9. Poor decision making; not think of consequences.	Y : N	1 2 3 4
10. Childish; at times behaviour is immature.	Y : N	1 2 3 4
11. Poor insight; refuse to admit difficulties.	Y : N	1 2 3 4
12. Difficulty in becoming interested in things.	Y : N	1 2 3 4
13. Lack of initiative; not think for myself.	Y : N	1 2 3 4

HEAD INJURY BEHAVIOUR RATING SCALE

1. The behaviour is a problem for the individual but causes me NO distress.
2. The behaviour is a problem for the individual and causes me MILD distress.
3. The behaviour is a problem for the individual and causes me MODERATE distress.
4. The behaviour is a problem for the individual and causes me SEVERE distress.

	BEHAVIOUR	Is the behaviour a PROBLEM?	How much DISTRESS does problem cause?
14.	Irritable; snappy; grumpy.	Y : N	1 2 3 4
15.	Sudden/rapid mood change.	Y : N	1 2 3 4
16.	Anxious; tense; uptight.	Y : N	1 2 3 4
17.	Depressed; low mood.	Y : N	1 2 3 4
18.	Irresponsible; can't always be trusted.	Y : N	1 2 3 4
19.	Overly sensitive; easily upset.	Y : N	1 2 3 4
20.	Lack motivation; lack of interest in doing things.	Y : N	1 2 3 4

Appendix 8

Name_____Date_____

BECK

Below are groups of statements headed A, B, C etc. Begin by reading all the statements in group A and then place a cross in the brackets next to the statement that best describes how you feel at the present. Then go on through the other groups in exactly the same say. On completion, please check that you have selected only one statement in each group and that every group has been covered.

	( )	I do not feel sad.
	( )	I feel blue or sad.
(A)	( )	I am blue or sad all the time and I can't snap out of it.
	( )	I am so sad or unhappy that it is very painful.
	( )	I am so sad or unhappy that I can't stand it.
	( )	I am not particularly pessimistic or discouraged about the future.
	( )	I feel discouraged about the future.
(B)	( )	I feel I have nothing to look forward to.
	( )	I feel that I won't ever get over my troubles.
	( )	I feel that the future is hopeless and that things cannot improve.
	( )	I do not feel like a failure.
	( )	I feel I have failed more than the average person.
(C)	( )	I feel I have accomplished very little that is worthwhile or that means anything.
	( )	As I look back on my life, all I can see is a lot of failure.
	( )	I feel I am a complete failure as a person (parent, husband, wife).
	( )	I am not particularly dissatisfied.
	( )	I feel bored most of the time.
(D)	( )	I don't enjoy things the way I used to.
	( )	I don't get satisfaction out of anything any more.
	( )	I am dissatisfied with everything.
	( )	I don't feel particularly guilty.
	( )	I feel bad or unworthy a good part of the time.
(E)	( )	I feel quite guilty.
	( )	I feel bad or unworthy practically all the time.
	( )	I feel as though I am very bad or worthless.
	( )	I don't feel I am being punished.
	( )	I have a feeling that something bad may happen to me.
(F)	( )	I feel I am being punished or will be punished.
	( )	I feel I deserve to be punished.
	( )	I want to be punished.

	( )	I don't feel disappointed in myself.
	( )	I am disappointed in myself.
(G)	( )	I don't like myself.
	( )	I am disgusted with myself.
	( )	I hate myself.

	( )	I don't feel I am any worse than anybody else.
(H)	( )	I am very critical of myself for my weaknesses or mistakes.
	( )	I blame myself for everything that goes wrong.
	( )	I feel I have many bad faults.

	( )	I don't have any thoughts of harming myself.
	( )	I have thoughts of harming myself but I would not carry them out.
(I)	( )	I feel I would be better off dead.
	( )	I have definite plans about committing suicide.
	( )	I feel my family would be better off if I were dead.
	( )	I would kill myself if I could.

	( )	I don't cry any more than usual.
(J)	( )	I cry more than I used to.
	( )	I cry all the time now, I can't stop it.
	( )	I used to be able to cry but now I can't cry at all even though I want to.

	( )	I am no more irritated now than I ever am.
(K)	( )	I get annoyed or irritated more easily than I used to.
	( )	I feel irritated all the time.
	( )	I don't get irritated at all at the things that used to irritate me.

	( )	I have not lost interest in other people.
	( )	I am less interested in other people now than I used to be.
(L)	( )	I have lost most of my interest in other people and have little feeling for them.
	( )	I have lost all my interest in other people and don't care about them at all.

	( )	I make decisions about as well as ever.
	( )	I am less sure of myself now and try to put
(M)		off making decisions.
	( )	I can't make decisions any more without help.
	( )	I can't make any decisions at all any more.

	( )	I don't feel I look worse than I used to.
	( )	I am worried that I am looking old or unattractive.
(N)	( )	I feel that there are permanent changes in my appearance and they make me look unattractive.
	( )	I feel that I am ugly or repulsive looking.
	( )	I can work about as well as before.
	( )	It takes extra effort to get started at doing something.
(O)	( )	I don't work as well as I used to.
	( )	I have to push myself very hard to do anything.
	( )	I can't do any work at all.
	( )	I can sleep as well as usual.
	( )	I wake up more tired in the morning than I used to.
(P)	( )	I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
	( )	I wake up early every day and can't get more than five hours sleep.
	( )	I don't get any more tired than usual.
	( )	I get tired more easily than I used to.
(Q)	( )	I get tired from doing anything.
	( )	I get too tired to do anything.
	( )	My appetite is no worse than usual.
	( )	My appetite is not as good as it used to be.
(R)	( )	My appetite is much worse now.
	( )	I have no appetite at all any more.
	( )	I haven't lost much weight, if any, lately.
	( )	I have lost more than 5 pounds.
(S)	( )	I have lost more than 10 pounds.
	( )	I have lost more than 15 pounds.
	( )	I am no more concerned about my health than usual.
	( )	I am concerned about aches and pains, or upset stomach, or constipation, or other
(T)		unpleasant feelings in my body.
	( )	I am so concerned with how I feel or what I feel that it's hard to think of much else.
	( )	I am completely absorbed in what I feel.
	( )	I have not noticed any recent change in my interest in sex.
(U)	( )	I am less interested in sex than I used to be.
	( )	I am much less interested in sex now.
	( )	I have lost interest in sex completely.

APPENDIX 9

Name_____ Date_____

STAI-Y1

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

(1) Not at all
(2) Somewhat
(3) Moderately so
(4) Very much so

1)	I feel calm	1	2	3	4
2)	I feel secure	1	2	3	4
3)	I am tense	1	2	3	4
4)	I feel strained	1	2	3	4
5)	I feel at ease	1	2	3	4
6)	I feel upset	1	2	3	4
7)	I am presently worrying over possible misfortunes	1	2	3	4
8)	I feel satisfied	1	2	3	4
9)	I feel frightened	1	2	3	4
10)	I feel comfortable	1	2	3	4
11)	I feel self-confident	1	2	3	4
12)	I feel nervous	1	2	3	4
13)	I am jittery	1	2	3	4
14)	I feel indecisive	1	2	3	4
15)	I am relaxed	1	2	3	4
16)	I feel content	1	2	3	4
17)	I am worried	1	2	3	4
18)	I feel confused	1	2	3	4
19)	I feel steady	1	2	3	4
20)	I feel pleasant	1	2	3	4

Name_____ Date_____

STAI-Y2

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you generally feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

(1) Almost never
(2) Sometimes
(3) Often
(4) Almost always

1)	I feel pleasant	1	2	3	4
2)	I feel nervous and restless	1	2	3	4
3)	I feel satisfied with myself	1	2	3	4
4)	I wish I could be as happy as others seem to be	1	2	3	4
5)	I feel like a failure	1	2	3	4
6)	I feel rested	1	2	3	4
7)	I am "calm, cool and collected"	1	2	3	4
8)	I feel that difficulties are piling up so that I cannot overcome them	1	2	3	4
9)	I worry too much over something that really doesn't matter	1	2	3	4
10)	I am happy	1	2	3	4
11)	I have disturbing thoughts	1	2	3	4
12)	I lack self-confidence	1	2	3	4
13)	I feel secure	1	2	3	4
14)	I make decisions easily	1	2	3	4
15)	I feel inadequate	1	2	3	4
16)	I am content	1	2	3	4
17)	Some unimportant thought runs through my mind and bothers me	1	2	3	4
18)	I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
19)	I am a steady person	1	2	3	4
20)	I get in a state of tension or turmoil as I think over my recent concerns and interests	1	2	3	4

Appendix 10

Name_____Date_____

STAXI

Part 1 Directions: A number of statements that people use to describe themselves are given below. Read each statement and then circle the appropriate number using the following scale to indicate how you feel **right now**.

(1) Not at all;
(2) Somewhat;
(3) Moderately so;
(4) Very much so.

There are no right or wrong answers. Do not spend too much time on any one statement, but give the answer which seems to **best** describe your **present feelings**.

1)	I am furious.	1	2	3	4
2)	I feel irritated.	1	2	3	4
3)	I feel angry.	1	2	3	4
4)	I feel like yelling at somebody.	1	2	3	4
5)	I feel like breaking things.	1	2	3	4
6)	I am mad.	1	2	3	4
7)	I feel like banging on the table.	1	2	3	4
8)	I feel like hitting someone.	1	2	3	4
9)	I am burned up.	1	2	3	4
10)	I feel like swearing.	1	2	3	4

Part 2 Directions: A number of statements that people use to describe themselves are given below. Read each statement and then circle the appropriate number using the scale below to indicate how you <u>generally</u> feel.

(1) Almost never;
(2) Sometimes;
(3) Often;
(4) Almost always.

There are no right or wrong answers. Do not spend too much time on any one statement, but give the answer which seems to <u>best</u> describe how you <u>generally</u> feel.

11)	I am quick tempered.	1	2	3	4
12)	I have a fiery temper.	1	2	3	4
13)	I am a hotheaded person.	1	2	3	4
14)	I get angry when I'm slowed down by others' mistakes.	1	2	3	4
15)	I feel annoyed when I am not given recognition for doing good work.	1	2	3	4
16)	I fly off the handle.	1	2	3	4
17)	When I get mad, I say nasty things.	1	2	3	4
18)	It makes me furious when I am criticized in front of others.	1	2	3	4
19)	When I get frustrated, I feel like hitting someone.	1	2	3	4
20)	I feel infuriated when I do a good job and get a poor evaluation.	1	2	3	4

Part 3 Directions: Everyone feels angry or furious from time to time, but people differ in the ways that they react when they are angry. A number of statements are listed below which people use to describe their reactions when they feel **angry** or **furious**. Read each statement and then circle the appropriate number using the scale below to indicate how **often** you **generally** react of behave in the manner described when you are feeling angry or furious.

(1) Almost never;
(2) Sometimes;
(3) Often;
(4) Almost always.

There are no right or wrong answers. Do not spend too much time on any one statement.

WHEN ANGRY OR FURIOUS....

21)	I control my temper.	1	2	3	4
22)	I express my anger.	1	2	3	4
23)	I keep things in.	1	2	3	4
24)	I am patient with others.	1	2	3	4
25)	I pout or sulk.	1	2	3	4
26)	I withdraw from people.	1	2	3	4
27)	I make sarcastic remarks to others.	1	2	3	4
28)	I keep my cool.	1	2	3	4
29)	I do things like slam doors.	1	2	3	4
30)	I boil inside, but I don't show it.	1	2	3	4
31)	I control my behaviour.	1	2	3	4
32)	I argue with others.	1	2	3	4
33)	I tend to harbour grudges that I don't tell anyone about.	1	2	3	4
34)	I strike out at whatever infuriates me.	1	2	3	4
35)	I can stop myself from losing my temper.	1	2	3	4
36)	I am secretly quite critical of others.	1	2	3	4

37)	I am angrier than I am willing to admit.	1	2	3	4
38)	I calm down faster than most other people.	1	2	3	4
39)	I say nasty things.	1	2	3	4
40)	I try to be tolerant and understanding.	1	2	3	4
41)	I'm irritated a great deal more than people are aware of.	1	2	3	4
42)	I lose my temper.	1	2	3	4
43)	If someone annoys me, I'm apt to tell him or her how I feel.	1	2	3	4
44)	I control my angry feelings.	1	2	3	4

Appendix 11

DETAILS/TYPES OF HEAD INJURIES SUFFERED BY THE CHI INDIVIDUALS (BRIEF OUTLINE).

SUBJECT 1
Diffuse damage from a severe fall. Right subdural brain contusion accompanied by parietal/orbital haematomas. Other injuries included thoracic vertebral fracture and socral fracture.

SUBJECT 2
Motor vehicle accident. A 'contre-coup' injury with significant contusions or bruising. Secondary damage was diffuse.

SUBJECT 3
A fall. 'Coup' to 'contrecoup' injury with secondary intracranial bleeding (subdural haematoma).

SUBJECT 4
Motor-bike accident. Diffuse intracerebral damage with secondary injuries.

SUBJECT 5
Hit by a vehicle. Diffuse axonal damage with secondary intracerebral bleeding.

SUBJECT 6
Hit by a steel beam. Broca's area (speech) affected most. Expressive and nominal dysphasia, dense expressive dysphasia otherwise neurologically intact.

SUBJECT 7
Hit by a vehicle. Fronto-temporal damage. Intracerebral haemorrhage. Large temporal lobe intracerebral haematoma, contusion over the posterior part of the inferior frontal gyrus on the left.

SUBJECT 8
Motor vehicle accident. Fronto-temporal contusions with intracranial pressure (edema). Other diffuse damage likely.

SUBJECT 9
Congenital defect with intracranial haemorrhage, no other secondary injuries.

SUBJECT 10
Motor vehicle accident. Hemispheric damage reported. Left-hand side of the brain affected the most with secondary bleeding.

SUBJECT 11
Motorbike accident. Diffuse axonal injury with intracranial swelling (edema). Diffuse secondary damage.

SUBJECT 12
Diffuse head injury - no additional information available.

SUBJECT 13
Motor vehicle accident. Diffuse axonal damage with intracranial swelling (edema).

SUBJECT 14
Motor vehicle accident. Brain stem affected the most, diffuse damage reported.

SUBJECT 15
Motor vehicle accident. 'Coup-contrecoup' injury with swelling (edema). Temporal lobe most affected.

SUBJECT 16
Motor-bike accident. Diffuse fronto-temporal contusions reported.

SUBJECT 17
A Fall. Diffuse axonal damage with intracerebral bleeding, subdural haematoma.

SUBJECT 18
Motor vehicle accident. Diffuse fronto-temporal damage reported with swelling (edema).

Appendix 12
CODING SCHEDULE
FOR PHYSICAL AND COGNITIVE SCALES

AREAS OF DIFFICULTY AS PERCEIVED BY RELATIVES / CHI ADULTS

	No Loss	Mild Loss	Moderate Loss	Markedly worse
AUDITORY				
TACTILE				

VISUO				
SMELL & TASTE				
MOTOR FUNCTION				

Appendix 13

CODING SCHEDULE (frequencies recorded) FOR BEHAVIOURAL SCALE

An example

HEAD INJURY BEHAVIOUR RATING SCALE AS PERCEIVED BY FAMILY MEMBERS'

n=10

Behaviour	Is the behaviour a problem?		How much DISTRESS does the problem cause?			
	Yes	No	1	2	3	4
Anger, difficulty ntrolling temper	7	3	3	2	-	2
Impatience, upset hen needs not easily et	8	2	-	6	-	2
Frequent complaining	1	9	-	1	-	-
Aggression, violent haviour	2	8	1	1	-	-
Impulsivity:things ithout thinking	7	3	1	3	1	2
Argumentative: often spute topics	4	6	-	-	2	2
Lack control over haviour; behaviour is appropriate for social tuations	3	7	-	-	2	2
Overly pendent;rely on others ıneccessarily; does not things for myself	2	8	1	-	1	-

Poor decision aking; not think of nsequences	5	5	-	2	2	1
. Childish; at times haviour is immature	5	5	-	3	1	1
.. Poor insight; refuse admit difficulties	5	5	-	-	3	1
. Difficulty in coming interested in ings	2	8	-	-	2	-
. Lack of initiative; t think for myself	3	7	-	2	1	-
. Irritable; snappy; umpy	5	5	-	3	2	-
. Sudden/rapid mood ange	3	7	1	1	-	1
. Anxious; tense; tight	5	5	-	3	-	2
. Depressed; low ood	5	5	-	2	1	2
. Irresponsible; can't ways be trusted	1	9	-	-	1	-
. Overly sensitive; sily upset	4	6	-	1	1	2
. Lack motivation; ck of interest in doing ings	3	7	1	1	1	-

Note: the Head Injury Behavioural scale is appendisised (appendix 7.)

Appendix 14

Advertisement placed in the Christchurch local Newspaper 'The Press" in an effort to recruit subjects

Head Injuries

Persons who have suffered closed head injuries (internal head injuries) two years ago or more, are invited to participate in a study of their opinions about the effects of the injury and the help they may have received. The study is being done by Nishi Parkhill, a graduate student at the psychology department of the University of Canterbury. Relatives,close friends, or partners are also invited to participate. The nates of participants will be kept confidential, and will not be included in any documents used in the research. Details from Nishi Parkhill at 3515488 after 5 pm.

Appendix 15

CLASSIFICATION:

Duration of Post Traumatic Amnesia (PTA)
PTA refers to the length of time between the head injury and the return of continuous memory for everyday events (e.g. who visited yesterday, what was eaten for tea). A head injury is severe when the length of PTA is longer than a day. The relationship between severity of injury and length of PTA is detailed below.

Less than 5 minutes	very mild
5 to 60 minutes	mild
1 to 24 hours	moderate
1 to 7 days	severe
1 to 4 weeks	very severe
more than 4 weeks	extremely severe